Deinstitutionalization and its Effects on Social Inclusion, Choice-Making, Adaptive and Maladaptive Behavior for Individuals with Intellectual Disabilities: Case Studies Analysis

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Abstract

In the past three decades institutions for persons with intellectual disabilities (ID) have been downsizing and closing in Ontario, Canada. This trend is reflective of the changes that have occurred in society. As of March 2009 the last institution operated by the Ontario government for persons with ID closed, placing the remaining approximately 1000 persons into the community.

The current study was an analysis of part of one study in a four-study research project, called the Facilities Initiative Study, to explore the impact of the closures on the lives of individuals who have been reintegrated into community settings. The goal of the current case study analysis was to describe the impact of changes in social inclusion, choice-making /autonomy, and adaptive/maladaptive functioning of four individuals prior to and following transition to the community. The results suggested that, in most cases, community integration was related to more social inclusion opportunities and autonomy in choice-making, a wider range of adaptive behaviors and fewer maladaptive behaviors. In some cases, the evidence suggested that some of these indices of quality of life were not improving.

Overall, the study found that the differences observed were unique to each of the individuals who participated in the case study analysis. Some generalized themes were generated that can be applied to future deinstitutionalization endeavors.

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INTRODUCTION

The final phase of the deinstitutionalization of persons with intellectual disabilities (ID) and reintegration into communities represented the end of government operated institutional living in Ontario, with the last closures occurring in March 2009. As a result of the deinstitutionalization, persons with ID were in the process of achieving full rights of citizenship, according to the United Nations charter of rights (Makharadze, Kitiashvili & Bricout, 2010).

Predictably, this shift in ideology was the impetus for mass changes in the nature of how persons with intellectual disabilities were integrated and accepted into their communities. Thus it was important to acquire knowledge about the factors that relate directly to the quality of the lived experience of persons with intellectual disabilities.

Numerous studies have examined the benefits and detriments of deinstitutionalization measured through indices such as social inclusion, autonomy and choice-making and adaptive/maladaptive behavior. In general, the trends suggest that most of these indices show improvement in individuals who have left institutions suggesting that community integration was a benefit to persons with ID (Molony & Taplin, 1988; Lemay, 2009). However, deinstitutionalization remained a controversial topic (Kim, Larson & Lakin, 2001) because the results have been mixed.

Few studies have applied a qualitative approach to exploring how social inclusion, choice-making/autonomy and adaptive/maladaptive behaviors have changed as a result of deinstitutionalization. The present study was designed to contribute to that knowledge base.

The purpose of this case study analysis, as part of the Facilities Initiative project, was to qualitatively investigate the lives of four individuals who were transitioned from an

institutional life setting into a community residential setting. The goal was to capture their life stories in terms of appreciating how the process of deinstitutionalization had affected the lives of four individuals as it relates to social inclusion, the opportunity for making choices, and their adaptive and maladaptive functioning.

Literature Review

The History of Deinstitutionalization

The movement towards deinstitutionalization in North America was inspired by the theory presented in Wolfensberger's (1972) Principle of Normalization in Human Services. The theory of normalization proposed that, regardless of ability, all individuals should be entitled to the same opportunities, social supports, and sense of belonging with a well-balanced community, defined by equal access to resources, and not characterized by duress. This theory presented the notion that persons with ID should be able to effectively integrate into their communities and have access to appropriate therapeutic and social amenities, where necessary, thereby empowering their choice-making, increasing their functional independence and providing opportunities for them to engage in all aspects of community living (Van Houten et al., 1988).

Deinstitutionalization represented the opportunity to formulate and nurture ideals that were intrinsically valuable, and centered around autonomy, well-being and self-acceptance (Davidson, 2009), thereby fostering empowerment and increasing the quality of life for persons with ID. The goal was authentic integration into their communities and access to appropriate therapeutic and social amenities.

In comparison to the United Kingdom (Emerson & Hatton, 1994; Kozma, Mansell, & Beadle-Brown, 2009), Australia, New Zealand (Young & Ashman, 2004; Young, Sigafoos, Suttie,

Ashman & Grevell, 1998) and the United States (Kim, Larson & Lakin, 2001), there has been relatively little research in Canada, and Ontario in particular, on the impact on the lives of persons with ID following deinstitutionalization (Lemay, 2009). Although much of the research in other countries has shown improvement in adaptive behavior (Spreat & Conroy, 2001), changes in choice-making and autonomy (Heller, Miller & Factor, 1999), and increased social inclusion (Alphen, Dijker, Van Den Borne & Curfs, 2010), many of the earlier studies were based on individuals who demonstrated minimal challenges behaviorally, psychiatrically, or medically. Later studies, however, demonstrated that the degree of challenge did not affect the quality of the improvement for individuals who have been transitioned to the community (Efthimiou & Lemanowicz, 1982). This means that it is possible to establish and maintain positive and adaptive services, even for those people considered to present the greatest challenge to services. Community-based supports appear to be both viable and effective for people with severe challenging behavior, although there is concern that such services may lack effective managerial and professional support and, as a result, may be susceptible to breakdown in response to short-term crises (Golding et al 2009). Overall, superior outcomes may be associated with community-based provision that does not congregate together people with challenging behaviors.

In Canada, the progression of deinstitutionalization for persons with ID has been widely encouraged and adopted throughout the last three decades (Smith, 1981; Johnson & Traustadottir, 2005). More specifically in Ontario, following decades of multiple phases of downsizing and facility closures, the last three government-operated institutions were closed in March 2009 (Lemay, 2009). Correspondingly, in the final phase approximately one thousand individuals with ID became part of a process known as the Facilities Initiative (Griffiths, Condillac & Owen, 2011). The Facilities Initiative proposed to relocate the

remaining institutionalized individuals into residential options in community settings. Among the individuals who were relocated were persons who had behavioral or psychiatric challenges, high medical needs or fragility, and needs affiliated with age and a lifetime of institutionalization.

Corresponding with the goals of normalization, the outcomes of deinstitutionalization should include improved adaptive functioning, increased social inclusion and community involvement and enhanced choice-making and autonomy. However, given the lifelong experiences of institutionalization and the high level of personal needs, the outcomes for the final 1000 persons with ID returning from the institutions remained an empirical question. In the sections that follow, the research on maladaptive/adaptive changes in behavior, social inclusion and community involvement, and choice-making/autonomy are reviewed.

Research studies on changes in Adaptive/Maladaptive Behaviors

Adaptive behavior describes the ability to cope with environmental stressors, thereby facilitating an increased quality of daily life (Grossman, 1983; as cited in Hatton et al., 2001). It refers to the individual's physical, intellectual and communication abilities. Thorn, Pittman, Myers, and Slaughter (2009) showed that adaptive behavior was mediated by intelligence and was a consistent predicator of sustained social integration. Higher levels of adaptive behavior usually relate to improved community integration (White & Dodder, 2000).

In general, studies have reported a pattern of increased adaptive functioning in persons with an intellectual disability following deinstitutionalization (Felce & Repp, 1992; Lowe et al., 1993). For example, Lynch, Kellow and Wilson (1997) observed in their meta-analysis of adults with intellectual disabilities that the most obvious increases in adaptive functioning were related to self-care skills. Furthermore, Heller, Miller and Factor (1999)

reported in their study that increased adaptive behaviors were directly related to increases in community participation and autonomy or choice-making. A few studies have also observed that adaptive gains tended to peak and then plateau due to multiple factors such as level of ID (Molony & Taplin, 1990) and inconsistent support systems (Dagman, Ruddick & Jones, 1998). Spreat and Conroy (2001) demonstrated a significant effect size in their evaluation of the general adaptive behavior changes for adults with ID who had been recently deinstitutionalized from a facility. According to Dagman, Ruddick and Jones (1998), inconsistent support systems describe the fact that the early and positive changes evidenced may have been a result of impact of the move and the immediate changes in opportunities that it represented. However, the following decline in these positive changes may have been a result of the fact that the initiation of opportunities may have been inconsistent and support systems were unable to maintain this effort. For example, this study found in their results that the level of choice making opportunities offered from staff increased in the two and a half years after transition, but significantly declined thereafter, which the study suggested was typical of other such longitudinal studies.

In contrast, other studies have observed a pattern of declining adaptive behavior post deinstitutionalization (Calapai, 1988; Fortune et al, 1995; Stancliffe et al., 2002). A similarly mixed pattern had been observed for maladaptive behaviors as well (Conroy, Garrow, Fullerton & Brown, 2002).

An important component of sustained adaptive behavior in the community has been noted to be an emphasis on teaching functional skills such as the acquisition of domestic and personal skills to increase actual and perceived levels of functional independence (Molony & Taplin, 1990). Teaching functional skills was found to provide the opportunity for the

individual to build a relevant skill set and experiences in practical application of the acquired skill set (Thorn, Pittman, Myers & Slaughter, 2009).

Furthermore, although deinstitutionalization has been generally associated with increased adaptive functioning (Hundert, Walton-Allen, Vasdev, Cope & Summers, 2003), few studies have been conducted on the deinstitutionalized adaptive functioning of elder persons with an intellectual disability who lived in institutions for extended lengths of time (Lowe, De Paiva, & Felce, 1993.

In contrast, findings regarding the positive impact of deinstitutionalization on maladaptive behaviors of persons with ID have been less consistent in the research (Hundert, Walton-Allen, Vasdev, Cope & Summers, 2003; Young & Ashman, 2004). For example, Conroy Efthimiou, and Lemanowicz, (1982) observed that adaptive gains resulting from community integration did not moderate the relationship with maladaptive behaviors. Others have observed (Young & Ashman, 2004) that maladaptive behavior initially decreased following community placement, but subsequently increased after an extended period of community living.

Maladaptive behavior, including challenging behaviors such as self-injury (SIB), aggression, temper tantrums, property destruction, hyperactivity and extreme attention seeking behaviors, have been found to be displayed more often by males with an intellectual disability (Emerson, et al., 2001). Whereas SIB, a directed effort towards self-harm, has been most commonly evidenced in individuals with more severe levels of intellectual disability. Aggression has tended to focus on harming others and has been most commonly displayed in individuals with less severe levels of intellectual disability (Lemay, 2009).

While many studies have suggested that maladaptive behaviors decreased after deinstitutionalization, a meta-analysis of deinstitutionalization research, conducted by Lemay

(2009), demonstrated that results have been mixed. Some studies found that maladaptive behavior initially decreased after community placement, but subsequently increased after an extended period (Young & Ashman, 2004). Kim, Larson and Lakin (2001) found in their meta-analyses that maladaptive behaviors declined to statistically significant levels in one study by Conroy, Feinstein and Lemanowicz (1988), which used a control group, to enhance internal validity. While another study cited by Kim et al., (2001) found evidence of statistically significant increases in maladaptive behaviors post deinstitutionalization (Feinstein, Lemanowicz, DeRosa & Clarke, 2000). The research further identified that maladaptive behavior was directly related to the degree of social inclusion (Blacher & McIntyre, 2006; Cooper et al., 2009), in that individuals with maladaptive behaviors experienced some degree of social exclusion that was directly related to the degree of their challenging behaviors. Furthermore, the study by Blacher and McIntyre (2006) found that individuals with a high maladaptive behavior profile caused increased familial stress including overextension, familial depression. In short, the caregiver burden may lead to other adverse reactions, like an inability to seek out social alternatives and further isolation due to lack of informal supports.

Within the institutions, the general methods of treatment were physical and chemical restraint, as well as various forms of deprivation and confinement (Emerson, Beasley, Offord & Mansell, 1992). On the other hand, in community residential settings, direct care supports have been reported to involve therapeutic interventions that uphold a philosophy that persons with an intellectual disability have the right to a safe, person centered therapeutic environment, employing the least restrictive, but most effective treatment strategy (Van Houten, et al., 1988; Feldman, 1990). Applied behavioral analysis had been presented as a critical treatment approach for treatment of challenging behaviors; the goal being to deter

maladaptive behavior by replacement with functional adaptive behaviors (alternative or competing) also in an effort to enhance the quality of the lived experience for persons with ID in integrated community settings (Feldman, 1990).

As noted above, the individuals involved in the Facilities Initiative often had moderate to severe levels of intellectual disability, long histories of institutionalization, and a combination of associated behavioral/psychiatric and medical issues, including aging (Griffiths, Condillac & Owen, 2011). It therefore would extend the current literature to explore how individuals with these varying and complex needs respond differently relative to their adaptive and maladaptive behaviors after moving from an institution to a community setting

Research Studies on Social inclusion/Community Integration

Social inclusion describes feelings of valuation, attachment and an intrinsic sense of belonging in one's community of residence (Abbott & McConkey, 2006). In contrast, the proliferation of institutionalization was based on social control of persons with intellectual disabilities within society (Sheerenburger, 1984). The institutional setting presented limited opportunity to relate or integrate with the larger community.

Social inclusion for individuals with intellectual disabilities has been influenced by a variety of factors, such as the existing laws within the community, socio cultural norms, value systems and government funding to create and maintain programs (Makharadze, Kitiashvili & Bricout, 2010). In general, the evidence regarding the social inclusion of persons with intellectual disabilities has been mixed. While some studies have reported increased social inclusion following deinstitutionalization (Dagnan, Ruddick & Jones, 1998), others have argued that in some important aspects of their lives, persons with ID were still socially

excluded from activities (Myers, Ager, Kerr & Myles, 1998; Abbott & McConkey, 2006; Ware, Hopper, Tugenberg, Dickey & Fisher, 2007). However, the voice of the person with ID has been largely absent from debates as to how greater social inclusion could become a reality (Abbott & McConkey, 2006).

Social inclusion has been represented as the opportunity for persons with an intellectual disability to formulate and nurture ideals that are intrinsically valuable, and centered on autonomy, well being and self-acceptance (Davidson, 2009). Social inclusion has been enhanced by positive and valued social relationships within the community setting and acceptance from surrounding neighbors (van Alphen et al, 2010). These ideals have been associated with empowerment and increased feelings of dignity and life satisfaction, which are overall indicators of quality of life (Neely- Barnes, Marcenko & Weber, 2008).

The elaborated benefits of social inclusion have been numerous, including social support and acceptance, personal satisfaction and opportunities for gainful employment (Halpern, Nave, Close & Nelson, 1986). According to Hall (2010), some of the goals of social inclusion should be to provide persons with an intellectual disability with the same opportunities as typical members of the community to get a job, self-actualize as individuals, spend time with family and friends, enjoy life and get the extra support necessary to do this.

Moreover, the communities in which people with ID have been placed have been noted to also benefit from the inclusion of persons with intellectual disabilities into community and social settings (Cummins & Lau, 2003). Social inclusion has been able to increase the visible profile of disability issues within the community and has elevated the level of social consciousness within society. It has been postulated that the inclusion of persons with ID in the community has the potential of elevating social understanding and compassion for all

individuals, most especially persons with intellectual disabilities, who have historically been segregated, stigmatized and marginalized from society (Cummins & Lau, 2003).

One of the conundrums with social inclusion as it relates to deinstitutionalization has been that although integration has been identified as a critical goal for persons with ID, the reality has been that many individuals living in group homes, for example, have tended to have very small social networks consisting mainly of staff and family members (McConkey & Collins, 2010). Although individuals with ID have been relocated to the community, they have typically experienced less interaction with neighbors or others in their larger communities, as compared to non-disabled individuals.

Cummins and Lau (2003) noted that persons with intellectual disabilities have been relatively isolated and disconnected from the social context in their community settings, just as they were in their institutional settings. Although numerous studies have demonstrated that community-based residential homes have been vastly superior to institutional dwellings (Young, Sigafoos, Suttie, Ashman & Grevell, 1998; Kim, Larson & Lakin, 2001; Kozma, Mansell & Beadle-Brown, 2009), it has been argued that group homes embedded in the community as a means towards community integration have insufficient support structures to ensure social inclusion (Wituk, Pearson, Bomhoff, Hinde & Meissen, 2007). In some cases living in the community has been as socially isolating as the institutional settings (McConkey & Collins, 2010).

Authentic inclusion has been said to embody realistic and valued depictions of disability woven into the fabric of mainstream society (Lemay, 2006). According to Mansell and Beadle-Brown (2010), acceptance and assistance of persons with intellectual disabilities from community members without thought of remuneration has emerged as an important element to facilitate the ease of acceptance of the various natural roles that community

members can play in the lives of persons with intellectual disabilities such as neighbors, co-workers and friends. This level of social inclusion has been reported as a buffer against social isolation (Lemay, 2006).

One of the barriers to sustained social integration has been the fact that poverty is the single most disabling condition for persons with ID. The level of socioeconomic support means that many persons with intellectual disabilities have struggled to afford the things that were necessities for non-disabled people, much less the training/education, transportation or clothing that might enable them to participate more fully in public life (Wendell, 1996). Poverty and powerlessness have been identified as cornerstones of the dependency that persons with ID experience and have been crucial in both constructing and maintaining disability oppression (Charlton, 2006).

Social inclusion has also been associated with the level of functional independence of the individual in question (Perry & Felce, 2003; Thorn, Pittman, Myers & Slaughter, 2009). Research by the above named authors has demonstrated that individuals with greater intellectual challenge were less socially integrated as compared to individuals with milder levels of disability.

Thus full social inclusion, which can be described as full immersion in communities and making efforts to become familiar with the people and places in the community of residence, although paramount to the goals of deinstitutionalization, has been challenging for the field to accomplish. Although the lack of functional independence has been noted as important to social inclusion, other factors such as transportation, lack of a political voice and poverty have also been shown to play a vital role in whether the transition to the community has resulted in community inclusion or continued isolation (Ware, Hopper, Tugenberg, Dickey & Fisher, 2007).

Research Studies on Changes in Choice and Autonomy

When offered adequate supports and guidance, persons with intellectual disabilities have been able to be empowered to make choices regarding their lives (Bradley, 1994) and to make more self-determined choices (Nota, Ferrari, Soresi & Wehmeyer, 2007). However, opportunities to make self-determined choices have been reportedly limited (Antaki, Finlay, Walton & Pate, 2008) and vary depending on the nature of the setting. Some studies have indicated that semi-independent living (Stancliffe, Abery & Smith, 2000), independent living (Wehmeyer, Kelchner & Richards, 1995), and smaller group residences with less than 5 residents (Tossebro, 1995) posed ideal settings to foster increased choice-making. Many other issues that have been shown to affect choice-making for persons with intellectual disabilities living in community and residential settings were related to policies and procedures that posed conflicts with the support workers' ability to offer a wider range of choices, and inadequate training to bridge the gap between differing communication abilities (Antaki, Finlay, Walton & Pate, 2008).

Choice-making has been described as empowering confidence in the decision- making skills of persons with an intellectual disability with respect to their capacity to live autonomously in the community (Wehmeyer & Bolding, 2001). The goal of empowering persons with an intellectual disability with autonomy in choice has also been aligned with the protection of the right to be free from exploitation as supported by various studies that reported that increased autonomy over one's life choices underscored increased self-efficacy and decreased learned helplessness (Wehmeyer & Metzler, 1995; Stancliffe & Abery, 1997). Wehmeyer and Bolding (2001) further noted that choice-making was dependent upon presentation of the opportunities within the social context to make choices. The perception

that persons with intellectual disabilities cannot make choices has been postulated to be a function of the failure of the social system to foster the appropriate opportunities for choice-making to occur rather than the ability of the individuals to learn to make choices (Heller, Factor, Sterns & Suttons, 1996).

An explanation for this trend could be attributed to the fact that historically and within the institutional setting, persons with intellectual disabilities were unquestionably assumed to lack competence. This observation was the foundation for the justification of rights restrictions such as the human right to live in a non-threatening environment, security, freedom of expression and self-determination (Griffiths, et al., 2003). Staff members from the institutions were generally expected to be responsible for making the decisions for the individuals who resided there (Asche, Blustein & Wasserman, 2008). However, Reid, Green and Parsons (2003) suggested that persons with intellectual disabilities have been denied the opportunity to make important choices that impact their daily lives.

Some of the issues presented as complications for independent choice-making have been related to the level of intellectual disability of the individual and the varying degrees of their communication ability. However, Neely-Barnes, Marcenko and Weber (2008) have noted that individuals who are non-verbal still maintain the ability to communicate in other ways, such as through the use of eye contact, gestures and other assistive devices, which can be quantified. However, persons with ID have been shown to rely on a limited range of solutions from past experiences on which to base decisions; the limits of their decision-making experiences may therefore not necessarily apply to a novel situation (Khemka, HIckson, Casella, Accetturi & Rooney, 2009). Moreover, research on the capacity for persons with intellectual disabilities to make decisions has reflected the fact that the decision-making skills of the individual with ID may be impaired pertaining to exercising rational judgments

regarding important decisions that impact their health and safety (Nazarko, 2004). As such, it has been cautioned that offering uninhibited choice capacity put both staff and the individuals at risk; the staff may be at risk for violating health and safety codes and the individual may consequently risk health or physical danger (Antaki, Finlay, Walton & Pate, 2008).

A recent approach used to empower self-directed choice making has been person centered planning. Person centered planning has been described as a way of involving the person in question at the center of their decision-making processes (Gervey, Gao, Tillman, Dickel & Kneubuehl, 2009). This approach involves listening to and learning about what the person wants for their life, and providing assistance in planning for current and future goals in a way that empowers the person in the decision-making process. The goal of person centered planning has been identified as a process whereby the individual receiving the service(s)has been placed in primary control of selecting and planning the services; self-determination has therefore been both encouraged and fostered (Neely-Barnes, Marcenko & Weber, 2008). The premise for person centered planning was based on the assumption that persons with intellectual disabilities preferred to make their own choices, which in turn created more adaptive life circumstances (Heller, Miller & Factor, 1999).

According to Lemay (2006), effective integration consistently manifests itself as an ambiguous concept, fraught with confusion in terms of how the concept can be most efficaciously applied. With the recent closures of the three remaining institutions in Ontario and the resulting integration of the remaining residents into the community, group homes and other supported living models have replaced the institutional setting for these individuals. The literature has suggested that the quality of their lived experience would be expected to have increased relative to institutional living (Molony & Taplin, 1988; Emerson & Hatton, 1996; Young & Ashman, 2004; Lemay, 2009), and as a result they would have experienced

greater inclusivity, enhanced richness of experience and improved interconnectedness within the social context (Shlalock, 2000).

Research Direction

The overall goal of the current research was to describe the change in choice-making opportunities, social inclusion and adaptive/ maladaptive functioning of four individuals involved in the Facilities Initiative pre and post deinstitutionalization as a way of understanding how this group of persons with ID experienced changes in their quality of life.

Due to the advanced age of the population involved in the Facilities Initiative, this study also proposed to highlight a gap in the literature as it pertains to this population in each of the areas noted. There has been a scarcity of research on older adults with ID (Hundert, et al., 2003) who have been recently deinstitutionalized. The population involved in the Facilities Initiative represented individuals of advanced age, moderate to severe mental disability, and who have histories of maladaptive behaviors/ psychiatric challenges and/or high medical physical needs. It was questioned whether the level of support required to promote their participation in choice-making and community inclusion would present unique challenges.

This study was designed to extend the existing body of literature within the field of deinstitutionalization research in Ontario by addressing the following research questions for a small number of individuals with intellectual disabilities who were followed over the course of one-year post deinstitutionalization. The literature has shown that the impact of deinstitutionalization has been evaluated in terms of the impact on adaptive functioning and challenging behaviors, the opportunities for self-determined choice-making, and changes in social inclusion. In other words, were maladaptive behaviors and autonomous choice-making

by persons with ID amenable to change after moving from an institution to a community setting? Furthermore, did this foster social inclusion in terms of the quality of the lived experience? The research questions used a qualitative method of inquiry to explore these same areas.

Research questions.

1. How have the opportunities for social inclusion changed for the individuals, pre and post deinstitutionalization?

2. What aspects of choice-making / autonomy changed for the individuals, pre and post deinstitutionalization?

3. How have adaptive behaviors changed for the individuals, pre and post deinstitutionalization?

4. How have the maladaptive behaviors changed for the individuals, pre and post deinstitutionalization?

5. How do the four factors listed above (social inclusion, choice-making, adaptive behavior and maladaptive behavior) interact across each individual case as related to the quality of their lived experience? (Cross participant analysis)

METHOD

Research Design

A multiple case study analysis was used, involving the use of a qualitative approach. This study incorporated the use of multiple methods such as questionnaires as well as structured interviews to facilitate the collection of data. Although questionnaires and quantitative measures were used as a means to gather information during the interviews, these data were not analyzed quantitatively. The use of multiple methods was implemented in order to provide additional support and validation for the qualitative approach.

The qualitative case study approach was an important research method in regards to this study because the lived experience of persons with ID has historically been excluded from the mainstream of research. This approach emphasized the importance of being able to take other people's perspectives into consideration and offered insight into the lived experiences of persons with ID beyond an exclusive focus on quantitative and diagnostic evaluations. The qualitative case study approach used in this study consisted of individual interviews of persons with ID, their family, direct care support staff, community agency administrative staff and facility planners, in addition to direct observations, validated questionnaires and a review of existing institutional documents which provided historical contextual information. This process of data collection has been commonly referred to as triangulation, which describes a repeated measures data collection method and critical analysis of the information gathered at multiple points in time in order to aid in the interpretation of the data (Stake, 2006).

The qualitative case study analysis also underlay and supported a focus on the "counter story". A counter story provided an informative means of representing a person in

his/her natural environment that allows researchers to gain an in-depth understanding of the presenting situations as related to their meanings for those involved (Goodley, 2000; Bjornsdottie & Svensdottir, 2008). Counter-stories were informative because they individualized each person's case such that the researcher was able to study the experience of each individual operating in each situation, independent of the experience of others.

This study represented one of four studies that were funded by the Ontario Ministry of Community and Social Services in order to assess the influence of deinstitutionalization on individuals with disabilities transitioned into community residences following the March 2009 closure of the last three institutions in Ontario. The results of this study may be useful for deinstitutionalization endeavors in other jurisdictions nationally and internationally. It may also inform researchers from an exploratory perspective, as to the adaptability of middle and older aged persons with ID in different environments, and as such, offers insight into the conditions that may be necessary in order to foster the most ideal transition in the future. For example, options for self-help, as well as empowerment and validation based on participation for such individuals who have spent majority of their institutional lives being told where to go and what to do. Central to the goal of deinstitutionalization for persons with ID is to develop their skills, abilities and attitudes that empower confidence in their decision-making skills and capacity to live autonomously in community. Sometimes the freedom to choose can be just as disempowering as not having choices, if you are not used to this approach. This may offer some insight into the inception or focus of behavioral programs.

Recruitment Procedure

The Ministry of Community and Social Services (MCSS) sent recruitment letters by mail to all potential participants within their residential agencies, family members or

substitute decision makers. The majority of the individuals involved in the Facilities Initiative were deemed unable to give informed consent, thus the appointed substitute decision makers were asked to give consent, after which informed assents were obtained directly from the participants at the beginning of each visit. The individuals who consented to participate were selected on the basis of their gender, age, medical and psychological needs in order to provide a representative sample of persons with ID who have been involved in the transition to community living as part of the Facilities Initiative.

Based on voluntary response to the recruitment invitations, a consent-to-contact form was then sent out to responding agencies, followed by a consent-to-participate form, which was sent out to the agencies and families alike. Overall, eight responses to participate in the Facilities Initiative Case Study were received and based on the scope of this thesis. Four of those individuals were randomly chosen for this study; the other individuals were included in another study. This study explored the experiences of those four individuals.

Of the four individuals in this study, two resided in the same home and were discharged from the same facility. The two other participants were discharged from other facilities and live in different geographic regions. The names of the participants have been changed to protect their privacy.

Measures

The Facility Planner Interview (Griffiths, 2007) was a 22-question interview that examined the planning process in order to assess the consistency of the planning process as related to the proposed outcomes for the individual case.

The Agency Administrator Interview (Griffiths, 2007) was a 10-question interview that explored the level of preparedness of the agency in terms of implementing the planned

procedure. It examined what supports were necessary as well as available for the agency to efficaciously accommodate the individuals, such as specialized supports and training as well as adequate funding.

The Direct Care Staff Interview (Griffiths, 2007) was a 43-question interview that explored the following domains that comprise of an efficacious and effective transition into community living, including: Adjustment/adaptation to the transition, setting and supports, daily routines, activities and community inclusion, changes since transition and quality of life.

Finally, the Family Interview, in which case involvement was optional, was a 14-question interview that was designed to assess the family members' perspective on the quality of the lived experience following the transition as well as the level of supports available within the new living situation. Overall, it explored the family members' feelings on whether the new placement was a good fit for their family member as related to adaptability, staff ratios, relationships, accessibility, choice and opportunities for increased social inclusion.

The standardized assessments comprised of five measures, including The Behavior Problems Inventory (BPI), The Current Management Strategies Interview (CMSI), The Scales of Independent Behavior Revised (SIB-R), The Inter RAI-ID and the Quality of Life Instrument Other Person or Self Report Questionnaire – Short Version (QOL).

The BPI (Rojahn, Matson, Lott, Esbensen & Smalls, 2001) was a 52-item questionnaire that measures self-injurious, stereotypic and aggressive/destructive behaviors for individuals with ID, encompassing all levels of functioning and ages. It was an informant-based questionnaire that was rated on two levels; namely, a five-point frequency of problem behavior scale (0 = never, 1 = monthly, 2 = weekly, 3 = daily, 4 = hourly) and a three-point severity of behavior scale (0 = no problem, 1 = slight problem, 2 = moderate problem, 3 = severe problem).

The CMSI (Feldman, Atkinson, Foti-Gervais, & Condillac, 2004) was an informant-based interview that investigated the presence of formal and informal behavioral interventions designed by qualified professionals and monitored by staff or caregivers implementing the interventions. More specifically, this interview was divided into two sections. The first section focused on the staff or caregiver information, the client's demographics, medications presently being administered to client, behavioral and emotional problems experienced by the client, the type of living environment and information regarding day program involvement. The second section focused on the formal and informal interventions encompassing such issues as the target problem behaviors, specialty of the professional who prescribed and monitors the intervention(s), methods of documenting the use of the interventions and effectiveness of the procedure with respect to stopping and preventing the problem behavior, teaching replacement behaviors and intrusiveness of the intervention (Feldman, Atkinson, Foti-Gervais, & Condillac, 2004).

The SIB-R (Bruininks, Woodcock, Weatherman, & Hill, 1996) was a measure of adaptive functioning and problem behaviors in a variety of domains. This informant based tool was comprised of 14 subscales including gross motor, fine motor, social interaction, language comprehension, language expression, eating and meal preparation, toileting, dressing, personal self-care, domestic skills, time and punctuality, money and value, work skills, and home/community orientation that assess the adaptive abilities, needs and problem behaviors according to severity and frequency of individuals across the life span.

The Inter RAI-ID (Martin, Hirdes, Fries, & Smith, 2007) was a 391 item interview that explored the status of individuals with ID across all levels of functioning, and all areas of life including: personal information, health service history, cognition, communication, hearing and vision, physical functioning and self-care, physical health, medications, skin condition,

oral and nutritional status, psychiatric diagnoses, mental state indicators, life events, behavior, psychosocial well-being and social supports, education, vocation, recreation, prevention and intervention and home environment. This tool provided information on outcome-based quality of services and information on identifying areas of strength, preference and needs of the individual.

The QOL – Short Version (Raphael, Brown, & Renwick, 1989) was an informant-based interview that gathered information on the extent to which individuals explore the full breadth of possibilities to participate effectively in their lives within the following three broad domains: Being, Belonging and Becoming. These three domains were further broken down into the following 8 subscales including physical being, psychological being, spiritual being, physical belonging, social belonging, practical becoming, leisure becoming and growth becoming, which were rated on a 5 point Likert-type scale (1 = not at all, 2 = a little, 3 = some, 4 = quite a bit, 5 = a lot).

Data Collection

Data was collected from each of the four participants at three points in time:

- Time 1: February – May 2010
- Time 2: October – December 2010
- Time 3: July – September 2011

Three time periods were selected in order to span a year of the person's life in order to gain a comprehensive picture. Due to schedules of both researchers and participants, the time span exceeded the anticipated period.

Pre deinstitutionalization data was acquired through the use of file review and questionnaire data (Inter RAI ID) to facilitate pre-post comparisons of the various facets that constitute quality of life.

Data collection consisted of four distinct facets including file review, direct interviews with community agency administrative staff, support staff and family members (optional), standardized assessments and direct observations. The file review consisted of a History Questionnaire (Griffiths, 2007) that was designed in order to gain insight into the life history of each of the individuals while they resided in the institutional setting. This questionnaire consists of the following domains: Behavioral/Psychiatric History, Biomedical History, Psychological History, Socio-cultural History, Behavioral Concerns and Comparison of the Historical account to the Essential Elements Plan.

The direct interviews were conducted by paired research assistants and consisted of four distinct interview templates, all of which were created in order to assess the outcome of the transitional process, in terms of the efficacy and effectiveness of the process, from the perspective of the individuals who were the most instrumentally involved in the process. These individuals included the Facility Planners, who organized the transition from the institution, the Community agency administrators, who received the individuals transitioning out of institutions into various residential support agencies, direct care or frontline staff and the family members who were given the option whether to participate or not.

After the visits were scheduled with a contact person or primary care counselor for the individual case study, packages were mailed to these persons containing the BPI, the SIB-R and the Behavior/Medical Status report. A comprehensive file review was conducted on each individual case prior to the person-to-person visits. During the person-to-person visits, both Research Assistants (RA) independently filled out all the standardized assessments with the assistance of the primary care counselor on behalf of the individual who was the focus of the case study. Semi structured interviews were conducted with the agency administrator, frontline care staff, facility planners and, if possible, family members. Direct observations of

the individual who was the focus of the study was also taken for the first 10 minutes of every hour for at least six hours in a typical day, including at least one mealtime. At the end of the day, both Research Assistants independently filled out a discrepancy analysis and an Assessor questionnaire, which was later compared for consistency.

Analysis

For the purposes of this thesis, a Qualitative Case Study Analysis was used by the author to describe the collection of life stories, pre and post institutional living for each of the four individuals. The collection of Life Stories involved observation, documentation and analysis of a typical day in the life of the person with ID in terms of accurately tapping into the context of their lived experience. The strength of this approach was the specificity of the information in relation to the individual, which enhances the practical relevance and usefulness of the information for the individual and their support network (Bjornsdottir & Svensdottir, 2008).

A deductive approach was used to analyze each of the cases. The case studies were reviewed focusing on the themes that were central to the research questions and using all of the sources of information including history, staff interviews, questionnaires and direct observation, in order to generate relevant themes. Single and multiple qualitative case analyses were used to deduce the information that was described in the results because the case study approach draws critical attention to complex relationships not otherwise adequately conveyed (Stake, 2006).

The case analysis strategy employed involved a methodical approach to carefully analyzing multiple sources of descriptive data, such as interviews, and direct observations, which then led to identification of the issue(s) to be examined further. It differed from other

ways of analyzing data in that it was very intensive in its descriptions (Hancock & Algozzine, 2006). In order to foster maximal understanding of each case, it was important to select issues or generate themes that were relevant to the individual life stories and that highlight the most relevant of their issues (Stake, 2006). This was achieved through systematic documentation of participant responses and other data collection methods.

The multiple case study analysis approach was used to look for commonalities or uniform ideas across the cases that were all focused around the research questions. An important reason for analyzing multiple case studies was because it offered the ability to observe the item of interest across various settings (Stake, 2006), which offered insight into the generalizability of the item of interest. This type of qualitative analysis allowed for illumination of issues that may inform practice and future research about the behavior of persons with ID. In general, the optimal number of participants for conducting a multiple case study analysis has been recommended as four or more (Stake, 2006), in which case, this study had an acceptable sample size to observe any interaction among the individuals and their situations.

RESULTS

The results were described in two ways: First each participant was described individually identifying their demographic information, their pre story from the facility and the post placement changes in their life relative to social inclusion, choice-making and adaptive/maladaptive behavior. Following the individual analysis, a cross participant analysis of these variables was undertaken.

Case 1: John

John was a 47-year-old Caucasian male who was generally described as being happy, content, and had a great sense of humor. Staff reported that John was most comfortable in a

calm setting with low noise levels. He was diagnosed with a profound intellectual disability. John enjoyed the following leisure activities, including family visits, bus rides, games and music, grocery shopping and meal preparation. Although John was able to speak and ask for things he wanted, in general his communication style was described as consisting of spontaneous speech and mostly echolalia. In other words, he used words but had limited speech with good diction. John lived in a residence with four other individuals all having different levels of functioning and mobility. His home was nicely furnished and laid out in an open concept with large windows in every room that allows for plenty of natural light, and an optimal view of the outdoors.

John shared a close relationship with his first cousin who reported that the quality of John's life was very good and much improved. John's cousin also reported that John appeared to enjoy his personal space and was much more relaxed as compared to the institution where John had to protect himself and his space much more intensely.

John lived in the institution for 45 years.

John's pre story

The information gathered from the retrospective institutional file review suggested that John's opportunities for social inclusion included a day program within the institution (Inter-RAI ID section C). In terms of the ability for decision-making or choice, John was described as rarely or never making decisions (Inter-RAI ID, section H).

In terms of adaptive behaviors while living in the institution, John's activity preferences included going for walks, dancing and watching television (Inter-RAI ID, Inter-RAI ID, section C). His primary communication method being verbal, his expressive and receptive communication abilities were described as being limited to making concrete requests and

responding to simple direct communication respectively (Inter-RAI ID, section G). In terms of his personal strengths, he was described as having a positive outlook, while lacking the ability to find meaning in day-to-day life (Inter-RAI ID, section D). With respect to routine activities around the home or community, such as housework and meal preparation, John was described as being totally dependent on staff support to perform such activities on his own (Inter-RAI ID, section J). Finally, in terms of his pre deinstitutionalization adaptive behaviors surrounding activities of daily living, John was described as being totally dependent on staff for his bathing and personal hygiene. Furthermore, he was assessed as needing oversight and cueing in order to dress his upper and lower body (Inter-RAI ID, section J).

John's maladaptive behavior assessment included the constant presence of anxiety manifested in the form of compulsive behaviors. Although not daily, John also engaged in behaviors, including wandering, physical abuse of others, self-injurious behavior, outbursts of anger and socially inappropriate behaviors

John's counter story.

Social inclusion.

In terms of opportunities for **social inclusion,** based on data from the first data collection period, John was able to say hello or shake hands when being introduced (SIB-R section C: social interaction). He regularly offered help to other people and enjoyed taking part in group activities or outings (SIB-R section C: social interaction). When he was immersed in a group setting he was able to reach out for a person in order to get their attention, which was an important skill to foster in a two or more way conversation. (SIB-R section C: social interaction). John attached some importance to the idea of social belonging and was somewhat interested in having friends and family to relate with (QOL section 5).

John was not employed and having access to community training and employment opportunities were not important to him (QOL section 6), but social opportunities such as bowling, basketball and shopping were important to him (Behavior/Medical Status 3).

In terms of access to social encounters, John was a very-laid back individual. Thus it was assumed by those involved in planning for him that the country rural lifestyle would be a good fit for him because the immediate surrounding neighborhood did not offer many opportunities for social inclusion and John did not appear to show any signs of what he wanted in terms of additional social inclusion opportunities (Assessor Questionnaire section 4).

John spent the majority of his daily interactions with staff and had been observed seeking out peers to join in community outings (Assessor questionnaire, section 5). John also enjoyed interactions with community members that he had developed a rapport with over the years at places such as the mall. He recognized people he was familiar with and would interact with them when approached (Assessor,, questionnaire, 5).

Typically, John attended an in-house day program, but staff was focused on getting a better understanding of what socially inclusive opportunities were important for John (Front line staff interview section D; Inter-RAI ID, section C).

Data from the second visit showed that John had started to place more value on family and friends and more thoroughly enjoyed his social time with them (QOL, section 5). He particularly enjoyed going to public places in his community and regularly had opportunities to participate in community training (QOL, section 6). John demonstrated increased social interaction in his ability to recognize and offer help to other people for example, holding the door open for a housemate (SIB-R, section C: social interaction). He was also fairly consistent with using proper manners when requesting and receiving items and did enjoy the company

of others (SIB-R, section C: social interaction). He loved to go for walks and participate in activities such as basketball fairly often (Assessor questionnaire).

John particularly enjoyed the outdoors but because his home was located in a rural area with no sidewalks, there was not much opportunity for him to go for walks. The main reasons were due to safety and walks were also largely dependent on the weather (Assessor Questionnaire, section 4). Moreover, possibly due to the nature of the rural area being a smaller community, it was reported that the community was not very open-minded regarding issues of disability (Assessor Questionnaire, section 5) or the idea of integration of persons with intellectual disabilities. This point was supported by reports of difficulty accessing medical professionals to service persons with an ID that were being supported by the agency (Frontline staff, section D). The majority of John's daily meaningful interaction was with the staff and his housemates (Assessor Questionnaire, section 5).

Other opportunities for social inclusion included John's increased access to community based employment opportunities such as a volunteer position at the food bank in addition to another work placement (Assessor Questionnaire section 4) (Inter-RAI ID section 3). In terms of community based leisure programs, John participated in Special Olympics baseball, basketball and bowling (Assessor Questionnaire, section 4), and also attended bingo regularly and went out to restaurants at least once a month (Frontline staff interview, section D).

John's day program also offered him numerous opportunities for social inclusion primarily due to the fact that it was individualized within a person centered approach (Frontline staff interview, section D). Therefore, it was uniquely suited to his strengths and capabilities. For example, he went swimming and rode the stationary bike on Fridays at the local gym, which he enjoyed very much (Frontline staff interview, section D). Albeit, there was always room for improvement and opportunities to be more involved (Frontline staff

interview, section D).

Data from the third visit showed that John was beginning to enjoy organized group activities, such as playing catch with a peer and other group games such as Wii. When involved in conversations, John was able to stay on topic and sustain his part in a conversation (SIB-R section C). The level of importance that John attached to family and friends generally remained consistent with each subsequent visit; he placed a high value on being socially connected. It was very important to John to have access to his social outlets in his community such as the shopping mall, churches, recreational facilities and local restaurants, where he was generally well known (QOL, social & community belonging).

Some new opportunities for social inclusion included visits with his siblings and cousin once a month, and a new volunteer placement. Overall, staff members stated that John had the potential to engage in more social opportunities in order to foster a deeper sense of inclusion. They were always looking for new social opportunities in which to include John, such as cooking classes (Front-line Staff interview). John was involved in volunteerism in addition to his day program and was seeking employment. Further evidence of a sense of inclusiveness was that John had become close with a particular peer. They seemed to have developed a rapport and looked out for one another. For example, they escorted each other to bed (Assessor Questionnaire, section 3).

Choice-making/autonomy.

From the first visit, the data demonstrated that there was a lot of variability in John's choice-making capabilities. On the one hand, he made quite a few decisions regarding how to spend his leisure time, but on the other hand, he did not exercise his right to make choices related to learning new things or when and how long he got to socially engage with family. In addition, he did not seem to exercise much choice in regards to having more or different

friends, or what neighborhood he lives in (QOL, section 4). Although John's verbal communication was predominantly echolalic, he was able to demonstrate and verbalize his choices and preferences (Assessor questionnaire, section 2). Before his move to the community, John had never lived in an environment that allowed him to fully exercise his choice-making capabilities. After the move he had full access to his home, particularly the kitchen where he actively chose and prepared his own meals with minimal supervision. This was a major step for John considering that food choices at one time seemed to trigger some problematic behaviors (Frontline staff, section D).

Overall, choice-making was a major part of John's life, from requesting certain edibles to verbally asking to go for a walk (Frontline staff, section E). His cognitive skills for daily decision making were described as requiring cues and supervision at certain times when self-directed decisions become poor or unsafe (Inter-RAI ID section H).

During the second visit it was observed that, in general, John's opportunities for choice-making or decision making had evolved. He did not exercise the option to make self-directed choices in the institution due to issues such as the sheer volume of individuals amongst many other reasons. However, since leaving the institution he exercised the option to make his own decisions and had numerous opportunities to do so. These choices tended to center around body care and hygiene, food, family and friends and how he spent his leisure time (QOL, questionnaire). For example, he was able to choose whether or not to dine at the communal table and also had free access to make his own food choices (CMSI, section E; Assessor Questionnaire, section 2). The latter issue was significant for John who had a weight issue in the past and did not always make the best food choices (Personal Care Plan; File Review). When he first moved into his current home, access to food in an open concept kitchen was difficult for him. With staff support and therapeutic intervention, this issue was no longer a

problem for him. He was able to exercise choice more confidently such that staff may ask him to do something and he may refuse to do it, which never happened when John first moved in (Frontline staff interview, section D). Overall, his cognitive skills for making daily choices can be described as difficult in new situations only and there had been no change in this regard in the 3 months prior to the second visit (Inter-RAI ID section H).

In terms of a typical day, John made most of his own choices and dictated the pace of his daily routine although he needed prompting at times (Assessor questionnaire, section 2). Staff made suggestions but he chose whether to follow their suggestions or not. For example, staff suggested that he begin his bathroom routine, but he maintained the choice of whether to have a bath or a shower. The same strategies were applied to what to wear or what to eat (Frontline staff, section E).

During the third visit, John demonstrated that he was able to adequately convey information about his likes. He made choices regarding most aspects of his life, which had increased since our initial meeting (Assessor questionnaire). For example, during dinner with housemates John made the random choice to say grace for the first time shortly before the third visit (Personal communication with staff, Aug, 2011). Other examples of increased choice-making included the choice on what time to wake and go to sleep, meal choices such as what to drink and what to have for dessert and snacks daily, daily clothing choices as well as sporadic changes during the day, the choice of whether and where to go in the community and what to buy when in the community. Finally, staff described that John would also make choices among staff, and go so far as to hand certain staff their jacket and ask them to go home (Frontline staff interview, section E). In other words he made the decision to ask them to leave his house.

Adaptive/ maladaptive functioning.

During the first visit, it was observed that John demonstrated an ability to cope with the typical stressors of life on a daily basis. He took pride in being clean and dressed appropriately on a daily basis and was involved in some physical activities (Assessor section 1). In terms of reliance on self or others, John was completely ambulatory and acted independently most of the time but required prompts and assistance to complete tasks in some cases (Assessor section 2). In general, John behaved confidently in some situations and communicated his needs as necessary (Assessor section 2).

John had a hard transition into his community residence initially. The residential reporting staff member described the transition as causing great anxiety for John, as he continually asked to be taken back to the ward (CMSI, section D) as well as for friends he made in the institution and was clearly missing. However, he adapted to the new setting quickly and now appears happy in his new home (Frontline Staff interview, section A). The time period for the transition was approximately one year. The staff hoped to gain a better understanding of what was important to and for John in order to empower him with a more active voice in how he now wishes to be supported (Assessor questionnaire, section D).

Overall, John was characterized as having a consistent positive outlook on life (Inter-RAI ID section D). In terms of his communication abilities, he was usually able to make himself understood but sometimes had difficulty finding words or finishing thoughts. He was also usually able to understand others but might have missed some part of the message (Inter-RAI ID section G).

In terms of instrumental activities of daily living, John was capable of preparing his own meals with limited assistance. He performed household chores with limited assistance but was capable of performing these tasks independently. He was completely dependent on

staff for his financial and medication management but a reporting staff member thought that he could be capable of requiring set up help only with his medications (Inter-RAI ID section J). In terms of activities of daily living, John was completely independent with such tasks as bathing, dressing, toilet use, mobility, and eating. He required some supervision and cueing with his personal hygiene (Inter-RAI ID, section J).

Based on the second visit, John appeared to be outwardly free from emotional problems. He behaved confidently and seemed sure of himself. He helped his housemates sometimes, for example, he was known to hold the door open for other housemates and also helped other housemates with their seatbelts when in the van. John accounted for his self-care independently (Assessor questionnaire, sections 2 & 3). Consistent with the evaluation from the first visit, John was assessed as being totally dependent on staff support for managing his finances and medications, but otherwise, was assessed as being capable of helping with meal preparation and housework with some level of assistance (Inter-RAI ID, section J), which was in addition to his capabilities compared to the first visit.

During the third visit, one of the clear differences was that John was able to attribute more meaning to life as compared to previous visits. (Inter-RAI ID, section D & G). John said hello when being introduced and was capable of using manners appropriately in conversation. He understood turn taking during conversation and group games. He was able to bathe and dress himself most of the time without being asked (SIB-R). He appeared comfortable to get what he wanted (such as food or change of clothing), when he wanted it and appeared to be generally settled (Assessor questionnaire).

In terms of his functional status, John was fully dependent on staff support in order to manage his medications and finances, but otherwise, had the capacity to only require oversight and cueing when preparing a meal, doing housework and selecting items during

shopping excursions. In addition, John was able to perform more than 50% of work related tasks, such as planning and performing the task, with staff support throughout the time

Relative to John's maladaptive behaviors, during the first visit, the data revealed that in the first year of living in a community residence, John demonstrated self-injurious behaviors such as bending his fingers backwards, hitting himself and property destruction which led to serious self-injury. After the first year's adjustment period, there had been no incidents of self-injurious behaviors. John exhibited some aggressive behaviors, which were described as overt and deliberate attacks towards others or objects. For example, in the past, John was known to rip clothing and throw furniture around the home (BPI). He could present a disruption to the environment as well. John had been caught stealing food, but the residential staff was not sure if there was intent to actually steal the food or if it was just a deeply ingrained institutional survival of the fittest response that overwhelmed him when he saw the food so he took it (BPI).

In general, John contended with some behaviors that were thought to be problematic within the dynamic of the residential setting such as destroying bedroom furniture and his bed in addition to destroying furniture in the common spaces of the home (CMSI, section D), which was interpreted as a form of intimidation (Inter-RAI ID, section L). As of the time of the final visit, John did not have a behavior program in place to address these issues (Behavior/Medical Status, 2). John also experienced episodes of panic or anxiety and demonstrated compulsive behaviors frequently. As part of his repertoire, he had bouts of verbal abuse, which could be described as incidents of yelling, cursing and threatening others. John also displays polydipsia, which was defined as excessive or inappropriate fluid consumption (Inter-RAI ID, section L).

Between the first and second visit, the data demonstrated that within the time period John did not engage in any self-injurious or aggressive behaviors. However he did engage in disruptive behaviors such as yelling and screaming as often as weekly (BPI, SIB-R: Problem Behavior section), as well as property destruction such as flipping or tearing furniture less than once a month. John was described as presenting with the following behaviors: crying and tearfulness, irritability, flat affect. He was described as persistently seeking attention, engaging in socially inappropriate, destructive, and compulsive behaviors as often as daily and lacking in goal directed motivation. Moreover, he was purported to engage in intense outbursts of anger persistently (Inter-RAI ID, section L).

Data from the third visit showed that, once again, John demonstrated some self-injurious behaviors such as finger and toenail pulling, which occurred approximately monthly, with slight severity. He also engaged in self-hitting, which occurred less than once a month. The reporting staff member considered this to be a slightly serious problem behavior. He demonstrated no aggressive behaviors, but engaged in yelling and screaming. This disruptive behavior occurred weekly, with slight severity as well (BPI). As a form of property destruction, John tore the stitching on furniture and threads on his clothing approximately less than once a month, which was also not considered a problem for the staff (SIB-R). Furthermore, John demonstrated agitated behavior (CMSI, section D).

As related to his mental state indicators, John was assessed as being irritable, having decreased energy and withdrawal from activities of interest, which occurred sometimes, but not with daily frequency. There were many behaviors that occurred with a higher frequency including sporadic bouts of motor excitation or hyper arousal, cheerful and happy facial expressions, compulsive behaviors, lack of motivation, unusual facial expressions, episodes of

panic and repeated verbalizations, outbursts of anger as well as intimidation of others. These behaviors tended to occur as often as 3 to 4 times a week (Inter-RAI ID, section L).

Case 2: June

June was a 54-year-old woman who was described as a patient person with a quiet demeanor who had an adventurous spirit and sense of humor, loved to laugh and had a beautiful smile. June was also very communicative with her eyes, which staff reported, "dance with curiosity" and sparkle with awareness. This signified to the staff that she understood the innuendos of the surrounding world. All who met June were quite taken with the gentleness that this person exuded and quickly became very fond of her. It was important for staff to know that June liked a quiet atmosphere and loved to be active, involved and interacting with new people. It was important to note that June was very observant and interested in taking in what was going on around her, often smiling at those in her vicinity.

June was diagnosed with a profound intellectual disability. She was non-verbal and non-ambulatory and completely dependent on her staff to meet all needs, including activities of daily living. June enjoyed special time with staff and especially enjoyed relaxing in a hot bathtub. She also enjoyed being fussed over and it was easy to recognize what was pleasing to her because she displayed a big smile and laughing that follow such displays of attention. June had very specific likes and dislikes surrounding food and was able to clearly communicate when she did not like what was being presented to her.

June lived in the institution for 38 years.

June's pre story.

According to the retrospective institutional file review, it appeared that June's opportunities for social inclusion included participation in the day program within the institution. Her social outlets included going for walks, where she was wheeled around, going to friendship club, shopping, watching television and listening to the radio (Inter-RAI ID section C). June's capacity to make decisions for her daily life was described as severely impaired, so that she never or rarely made decisions for herself (Inter-RAI ID, section H). In terms of adaptive behaviors, June's communication abilities were described as being quite compromised. She was rarely if ever understood and was assessed as rarely if ever comprehending others' conversation (Inter-RAI ID, section G). She was described as not having a positive outlook in addition to being unable to find meaning in day-to-day life (Inter-RAI ID, section D). In terms of her functional status, June was completely dependent on staff support to perform all her instrumental activities of daily living (Inter-RAI ID, section J). Furthermore, she was completely dependent on staff support for her activities of daily living (Inter-RAI ID, section J).

As related to maladaptive behavior, June's behavior was limited to sad facial expressions and nonverbal expressions of a lack of pleasure in life, which occurred more than 3 times per week (Inter-RAI ID, section L).

June's counter story.

Social inclusion.

The data from the first visit revealed that June had a pleasant and positive disposition. She appeared to interact in a meaningful way with family, friends, peers and community members (Assessor questionnaire). It was very important for June to feel close to someone in

her family and somewhat important for her to feel close to her friends. It was important for her to be able to go to her favorite places in the community, which included the shopping malls, restaurants and hair salon (QOL). She also attended church and friendship club regularly, and enjoyed movies and her women's hat club (Behavior medical status). June did not have the opportunity to feel a sense of inclusiveness in her immediate neighborhood because it was located on a rural country road and there were no neighbors within close proximity to socialize with (Assessor questionnaire). In terms of the appropriateness of June's daily activities, staff determined that because June was non-verbal, and therefore limited in her ability to give verbal feedback, staff engaged her in a variety of activities that they thought would be meaningful for her. Most of the feedback from June was based on body language, more specifically, June's ability to communicate pleasure or happiness through smiling (Frontline Staff questionnaire, section D). At the time of this first assessment she was involved in an in-house day program and was involved in the following activities: arts and crafts, wheeling outdoors, gardening, listening to music, religious activities, shopping and watching television (Inter-RAI ID, section C).

During the second visit, it was noted that June continued to participate in an in-home day program. At the time of this assessment she was involved in her hat club, lawn bowling, trips to the raceway and the usual things, which include shopping and restaurant dining (Behavior Medical status). Although the residence was located in a rural setting with no sidewalks to allow for safe wheeling, the area was quiet and had nice scenery that June appeared to enjoy as well, being someone who enjoyed a relaxed and tranquil environment (Assessor questionnaire, section 4). Opportunities for social inclusion could be optimized for June if she was able to live in town as opposed to the rural area. The agency reported that it would be more convenient to have the option to use the public transit as opposed to being

dependent on the van for travel into the community to engage in social opportunities (Agency Administrative staff).

Based on her capabilities, June interacted with peers and community members meaningfully and was well liked and accepted by others in her immediate living environment and in the larger community (Assessor questionnaire, section 5). Community-based education and employment options were not important to June, but it was important for her to have regular access to community based social outlets, which she did (Assessor questionnaire, section 6). In addition to the aforementioned activities, June also went to the library, grocery store and the casino. It was staff's ongoing goal to attempt to expand June's social circle and provide more opportunities for June to engage with her community (Frontline staff questionnaire, section D).

During the third visit, it was revealed that June had been appointed the queen of her chapter of the hat club and shortly before this visit she hosted a hat club treasure hunt (Behavioral/Medical Status); this was provided by staff as an example of increased social inclusion because she was well liked at regular social gatherings and well accepted by peers in her immediate living environment.

Choice-making/autonomy.

During the first visit, it appeared that June did not make a lot of decisions on her own, although there were a lot of opportunities for her to make decisions according to the staff. June did not have free access to the fridge because she was not ambulatory, but staff did offer limited choices to June, which reportedly worked well (CMSI section E). June was unable to act independently and relied wholly on staff to assist her in decision making and meeting her needs. Although June was non-verbal, she used facial expressions such as eye contact and smiling to communicate her choices (Assessor questionnaire). She showed no improvement

in this capacity since the transition into community living. In general, June's capacity for decision making was such that she rarely if ever made her own decisions, but the majority of choices she made related to food items as she would refuse to open her mouth for food that she disliked (Frontline Staff questionnaire, section E).

Data from the second visit showed that June made some decisions about her participation in casual leisure activities, but seemingly nothing else related to her physical being or her social or community belonging, for example. The goal for her staff as seen in their documentation of her needs, wants and preferences was to get to know her better and determine her choice preferences.

During the third visit, the staff continued to report that there were a lot of opportunities for her to take more active control of her the decisions that were made in her life (QOL).

Adaptive/ maladaptive functioning.

Overall, during all home visits June was appropriately dressed and groomed. When conversing with her, she gave full and sustained eye contact and enjoyed being involved in the group dynamics. More specifically, during the first home visit, June appeared slightly overwhelmed initially following the transition, which only lasted approximately 2 months. Since then, she had adapted very well to her new home and new housemates. She had also developed strong relationships with certain staff who transitioned with her from the institution as evidenced by the fact that she ate her meals better initially when the known staff were present. June engaged in floor exercises to encourage the continual use of her muscles as a means of being physically active (Frontline Staff questionnaire, section D). She was generally described as having a consistent positive outlook. Her expressive communication abilities were described as limited to making concrete requests and in terms

of language comprehension she was described as rarely if ever understanding others (Inter-RAI ID section G). In terms of her functional status as well as her activities of daily living, she was totally dependent on staff support to complete all of these tasks (Inter-RAI-ID, section J).

During the second visit, in terms of a level of self and other awareness within a social or group setting, June was very attentive to people in the room who were talking to her or otherwise. She was also attuned to a new or unfamiliar face in the room (SIB-R). Although she did not go out every day, staff was working towards the goal of expanding her social interests (Frontline staff interview, sections A & D).

During the third visit, although her adaptive behaviors remained generally consistent across the examination period, June demonstrated the ability to orient to people in the room or a conversation for a prolonged period to time and to follow the flow of the group (SIB-R). June also exuded a palpable sense of self-confidence and assurance.

June did not present with any maladaptive behaviors, however her affect consistently fluctuated frequently without any obvious explanation and she displayed crying, tearfulness and sad facial expressions (Inter-RAI ID section L).

Case 3: Sonny

Sonny was a 64-year-old man, best described as jovial and fun to interact with. He enjoyed one-to-one attention and smiled radiantly when receiving attention. He loved to tease and be teased back and was well liked by staff primarily due to his kind nature and his attentiveness to the needs of his housemates. He was described as having a general desire to help and reach out to those in need.

Sonny was diagnosed with a profound intellectual disability and bipolar mood disorder. He was verbally expressive and understood simple and direct conversations. He

was able to make requests regarding his wants and needs, such as the desire for food. He particularly enjoyed singing along to television jingles. His likes included desserts, music, watching sports and general social interactions.

As a result of extensive bio medical issues, Sonny was non-ambulatory and used a wheelchair. He was dependent on staff support to meet all his needs including completion of his daily living activities. Sonny's residence was part of a larger nursing home community, which he and his residential peers depended on for services such as meal support, daily living assistance, such as laundry support, as well as for participation in social and group activities.

Sonny lived in the institution for 44 years.

Sonny's pre story

According to the retrospective institutional file review, Sonny's opportunities for social inclusion included a day program in the institution. His activity preferences included many regular hobbies such as cards, games, puzzles, talking on the phone, arts and crafts, dancing, exercise, gardening, helping others, singing and listening to music and religious activities. Sonny was completely at ease interacting with others and participating in group activities. He avidly pursued activities in his residential setting or in the community with interest (Inter-RAI ID section C). In terms of his decision-making abilities, he was assessed as severely impaired, which means that he never or rarely made decisions for himself, which was consistent across time. Adaptively, in terms of expressive communication abilities, Sonny was described as having difficulty finding words or finishing thoughts, but he needed little or no prompting to communicate his needs and wants. In terms of his receptive communication abilities, he was assessed as missing some part of the message but comprehended most of the conversation, such that he was able to participate actively in conversations (Inter-RAI ID,

section G). Sonny reportedly had a consistent positive outlook and meaning in day-to-day life. He was completely dependent on staff support for routine activities around the home or in the community as well as in his daily living activities (Inter-RAI ID, section J).

In terms of maladaptive behaviors, Sonny's profile included irritability, negative statements, racing thoughts, labile and flat affect, lack of motivation, reduced social interaction and complete withdrawal from activities of interest. Sonny also demonstrated persistent anger at self and others as well as verbal and physical abuse, socially inappropriate and destructive behavior, intimidation of others and violence to others, outbursts of anger and he resisted care (Inter-RAI ID, section L).

Sonny's counter story

Social inclusion.

During the first visit, it became clear that it was very important for Sonny to have friends and be close to some people in his family (QOL). He enjoyed taking the bus into town for various medical and leisure related activities, visits with his family members and going to chapel for his connections group and music therapy (Behavioral medical status). In terms of a fit with the immediate neighborhood outside the home, Sonny was kept mostly separate from the other residents outside his residential suite due to being ostracized by the independent living senior residents of the nursing home. In fact, the senior residents signed a petition to expel Sonny from communal meal times and other social gatherings due to his sporadic outbursts of anger and swearing. In short, Sonny was not socially included in his immediate neighborhood outside of the residential suite. On the other hand, his co-residents in the suite had a clear rapport with Sonny and constituted the majority of Sonny's daily meaningful interactions. Sonny had limited access to community-based social services due to limited

access to transportation (Assessor questionnaire). Sonny was involved in an in-house day program. His activity preferences included an extensive list of activities such as gardening, arts and crafts, watching sports, and shopping (Inter-RAI ID section C).

Consistent with the first visit, it was clear during the second visit that Sonny enjoyed any and all opportunities for social engagement. He appeared to value a sense of belonging. He was able to command staffs' attention when necessary (SIB-R). Similarly, it was important to Sonny to have access to places in his community and to participate in a day program (QOL). Sonny had been enjoying bi-monthly visits with his mother and sisters, which had been very positive. He also enjoyed trips to the shopping mall (Behavior medical status). Although Sonny reportedly possessed a sense of belonging within the residential suite, he was still not socially included in the larger nursing home community within which the residential suite was embedded and dependent for essential services.

In terms of his larger community outside of the nursing home complex, Sonny enjoyed bus rides, going to parks, movies and shopping, but had experienced some negative reactions from community members due to his sometimes colorful and random dialogue. Staff was aware that due to a bipolar diagnosis, too much activity could be detrimental to Sonny's overall well being in terms of a rebound exhaustion effect. Staff members wished he could get out more often and participate in more activities during the daytime. For example, Sonny was involved in a new dog therapy program, which staff reported had resulted in him becoming more emotionally demonstrative (Frontline Staff interview).

Shortly before the third visit, Sonny had been reunited with a friend from the institution. They met at the mall and he thoroughly enjoyed his visit with her. They also made plans to get together again in the future (Behavior Medical Status). Although Sonny did not fit in with the neighborhood immediately outside his residential suite, staff had worked

hard to fill his day with other activities (Assessor questionnaire). In general, Sonny's regular activities were distributed between individual and group activities. Once a month, Sonny attended a drumming circle, which was a new activity for him (Frontline staff questionnaire).

Choice-making/autonomy.

Data from the first visit revealed that Sonny did make some decisions regarding his physical being, social and leisure activities and well being more generally. He had some, albeit not many, opportunities to improve his choice-making capacity. For example, he did not have the choice to move to a new residence, but had choice-making abilities over how he spent his time and with whom he spent it (QOL). Furthermore, Sonny did not have free access to the fridge even though he maintained the use of his hands and upper body in general (CMSI section E). Sonny was dependent on staff for direct care needs and was therefore unable to make choices independently (Assessor questionnaire). Sonny was considered to demonstrate some difficulty in new situations only, in terms of his daily decision-making capacity, which had been consistent for some time (Inter-RAI ID, section H).

During the second visit, it appeared that Sonny made some decisions about his social and leisure becoming and the food he ate, but very few choices regarding his physical being and belonging, which referred to where he lives and his space for privacy (QOL). Sonny did have free access to the fridge with staff support to gain access to his choices (CMSI section E). In general, Sonny behaved confidently and seemed sure of himself. He loved to be the center of attention. He made choices about what he watched on television and listened to on the radio. He communicated confidently about the things he liked although he may have been unable to act on them due to being wheelchair bound and thus fully dependent on staff assistance (Assessor questionnaire). Staff observed that Sonny made a conscious choice to take more initiative in participating in household activities. As such, staff members were

more mindful to offer him the choice to be included in household activities more often. Moreover, staff observed that Sonny initiated his leisure activity choices more than when he first moved into the residential suite. He also communicated his choice to go out of the suite for fresh air more frequently (Frontline Staff interview section E).

During the third visit, Sonny made quite a few decisions about most aspects of his life, with the exception of where he lives and the ability to move to another residence, as well as his hygiene and body care (QOL). Sonny did behave confidently and acted independently to some extent. He could feed himself but required constant assistance due to having stiff hands. He was able to tell about the things he liked and was eager to initiate conversation around topics of interest, including favorite programs and songs, for example (Assessor questionnaire). Sonny routinely made choices around movies and television programs, whether to go for a walk or do a puzzle (Frontline Staff questionnaire).

Adaptive/ maladaptive functioning.

During the first visit, Sonny was appropriately dressed and groomed at all times. He was not physically active at all. Sonny generally behaved very confidently. He could be very extraverted and loved to initiate interactions and physical contact in the form of hugs and handshakes with staff, peers and friends alike. In terms of his personal strengths, staff reported Sonny found meaning in his day-to-day life. He had difficulty finding words but if given time and with little or no prompting, he could finish expressing his thought. On the other hand, in terms of receptive language, he often understood the speaker, but may have missed some part of the message. Sonny was reliant on staff support for all of his activities of daily living, instrumental and otherwise. Although, he did have the capacity to use the phone and perform more than 50% of the task on his own (Inter-RAI ID).

During the second visit, it was observed that Sonny was capable of performing a work task for some time without stopping and was able to indicate when he had done. He had fairly good concentration when involved in a task, particularly puzzles. He could do this activity for at least 30 minutes at a time. He keenly avoided distractions and would ignore distractions if necessary. When completed, he would ask for another puzzle or whatever was the task at hand (SIB-R). He was always appropriately dressed and groomed. Staff reported that Sonny had adapted well to the transition. He knew that he had his own space and appreciated that. He was very outgoing when roaming the halls. He initiated physical affection from certain staff and was very willing to assist with household activities such as escorting staff to the laundry and waste management services, escorting staff to get his meals from the dining room, escorting other suite mates to their activities and assisting with general household chores, such as dishes and dusting (Frontline Staff questionnaire, section D). In terms of his activities of daily living, Sonny was totally dependent on staff support for his personal hygiene routine, wheeling and toilet use. However, he was able to perform some part of his bathing routine and could dress his upper and lower body on his own as well as swinging his legs in and out of his bed. He ate his meals mostly independently, but quickly lost interest and staff would assist in feeding him the rest of his meals when necessary (Inter-RAI ID section J).

During the third visit, Sonny was able to turn his head toward a speaker when his name was being called and was also able to consistently attend to people and conversations in the room. He was able to converse in three to four word sentences and had no problem naming familiar objects or concentrating on a puzzle for extended periods of time (SIB-R). Sonny appeared to be somewhat free from outward evidence of emotional problems, although he did engage in self-talk and random statements that did not seem to make sense (Assessor questionnaire).

During the first visit, it was noted that some of the behaviors that Sonny and his staff contended with included medication and food refusal and aggression towards staff (CMSI section D). In terms of his mood and mental state indicators, Sonny was dealing with multiple mood issues such as irritability and flat affect. He had anxiety related issues such as episodes of panic. He also experienced negative symptoms such as lack of motivation and reduced social interest. Furthermore, Sonny was dealing with some other behavioral symptoms such as persistent anger with self and others, verbal and physical abuse, and self-injurious behaviors (Inter-RAI ID section L).

Data from the second visit revealed that Sonny consistently contended with bipolar mood swings and anorexia that was directly related to bouts of depression (CMSI). The extent of Sonny's self-injurious behavior included hourly teeth grinding, which was considered to be severe. He scratched others about once a month. He also engaged in yelling and screaming behavior approximately weekly, which was considered to be severe. He engaged in the following moderately severe aggressive behaviors including hitting, kicking, pinching and being cruel as frequently as weekly. The most frequently occurring behaviors included grabbing and pulling, spitting, and verbal abuse, including swearing and the use of obscene language. These behaviors tended to occur daily and were considered to be severe. Otherwise, he engaged in throwing items daily, also a severe behavior (BPI & SIB-R). Other maladaptive behaviors, such as food refusal, usually occurred during bouts of depression.

Typically, Sonny displayed anxiety and anger during bedtime while staff assisted him with his bedtime routine (Behavior Medical Status). He also had numerous mental state issues that he contended with daily, including: mood and anxiety related issues such as expressions of guilt, irritability and episodes of panic, psychosis and negative symptoms such as hallucinations and expression of a lack of pleasure in life. He also displayed behavioral

symptoms such as persistent self-anger as well as anger toward others, socially inappropriate behavior and difficulty falling or staying asleep (Inter-RAI ID section L).

During the third visit, the data demonstrated that Sonny's yelling and screaming behavior had increased from weekly to daily. Disruptive behaviors, such as throwing food and banging items, made it important to use plastic dishes for Sonny's meals in order to avoid his periodic dish throwing during meals or his striking out and hitting or pinching staff. In such cases, where he was being hurtful to others, he was separated from his housemates in order to ensure their safety. He demonstrated socially offensive behavior through the use of vulgar language in public.

Case 4: Cherisse.

Cherisse was a 64-year-old woman who loved music and singing, dancing and going for walks. She very much enjoyed positive interactions that were calm and relaxing. She enjoyed being engaged in activities and was reported to be eager to attempt any activity offered to her. In general, Cherisse appeared to be most satisfied when left alone. She was best described as a loner who enjoyed staff attention in short intervals and enjoyed being the one to control her level of engagement with staff and peers. She was known to initiate back rubs and affection from staff, but it seldom occurred. Cherisse communicated using short sentences and phrases, picture boards and behaviors. She understood and mimicked simple commands and basic conversation. Cherisse was known to pick on those individuals who would not fight back and tended to demonstrate passive aggressive behaviors, such as sticking her foot out to trip staff/peers when annoyed. One of the best strategies for supporting Cherisse included working with the knowledge that she disliked changing activities with a quick transition and preferred to be given ample forewarning of impending changes. Her family was actively

involved in advocating for her medical health needs and routinely kept in contact with the staff.

Cherisse lived in the institution for 57 years.

Cherisse's pre story

According to the retrospective institutional file review, Cherisse was involved in an institutional day program. Her activity preferences included playing games, arts and crafts, music, singing and dancing, religious activities and watching television. Her cognitive skills for making daily decisions were rated as severely impaired, in other words she made no decisions for herself, which was consistent with her patterns of functioning. Her communication abilities were characterized as limited to the ability to make concrete requests, both expressively and receptively. Cherisse was assessed as having no personal strengths in terms of finding meaning in life or having a positive outlook on life. She was completely dependent on staff for all her functional abilities and capacities. In terms of her activities of daily living, although she was totally dependent on staff for her bathing, toileting and personal hygiene, she only required limited assistance for her dressing, bed mobility, locomotion and eating. Cherisse demonstrated very few maladaptive behaviors, including socially inappropriate behavior, resisting care and self-injurious behavior.

Cherrise's counter story

Social inclusion.

The first visit revealed that it was very important to Cherisse to be close to people in her family and to feel a sense of belonging. She also considered the places she goes in her community as related to her leisure activities to be very important (QOL). Cherisse did fit in

with her immediate neighborhood outside the home. It was a rural neighborhood with no neighbors nearby. In this rural setting, the property provided plenty of space for walking and the freedom to vocalize at will without worry of imposing on neighbors. On occasion however, there had been some complaints about her screaming from neighboring community members. Within the home, Cherisse related well with her housemates, whom she interacted with daily in a way that was considered meaningful. They frequently communicated their displeasure when she was vocalizing or throwing a tantrum. In general, meaningful interactions with community members did not appear to matter at all to Cherisse. She felt most included in one-to-one social and leisure activities such as shopping and going to restaurants or for picnics with a staff member (Assessor questionnaire), dancing, music and singing, watching television, going to church and walking outdoors (Inter-RAI ID, section C). She was involved in a day program within her home.

During the second visit, it was observed that Cherisse was often able to gain the attention of the person with whom she wanted to communicate. She imitated actions when asked, such as clapping her hands, and generally treated staff as friends (SIB-R). Consistent with the first evaluation visit, her family was important to her. She visited with them approximately once every six weeks. Because of the rural location, there was no sound restriction, which was helpful given constant yelling and screaming by Cherisse.

Cherisse's current home was not a perfect fit because although it was located on a vast property, it was not fenced, thus there was no opportunity for Cherisse to walk/wander outdoors in the yard. She was only somewhat accepted by her peers in the home because of the conflict that arose from her physically targeting her peers as well as her persistent screaming, which was not accepted by her peers who tended to prefer a calmer environment. It appeared that the screaming behavior also attracted stares from community members.

Although Cherisse did not interact meaningfully with people in her larger community, she did interact most often and most meaningfully with staff and was able to indulge in a few social activities daily, under ideal circumstances (Assessor questionnaire). Cherisse was not involved in any structured activity, such as a day program, but did have free access to community-based medical and social services.

In terms of the amount and appropriateness of social inclusion, staff reported that Cherisse could be more socially involved but it was difficult to transport her into the community when she was exhibiting problematic behaviors. There were also staffing limitations in terms of resources to support her and Cherisse did not demonstrate an active interest in many things (Frontline Staff questionnaire section D).

The third visit revealed that Cherisse was attempting some new activities such as camping. Staff was cautioned to keep the activities to a reasonable timeframe, as Cherisse tired easily. She also enjoyed sharing television time with her peers at her initiative (Frontline staff questionnaire section D).

Choice-making /autonomy.

During the first visit Cherisse made a lot of choices and decisions that were based on her daily activities such as the places she went in the community and socializing in general. Also, she made decisions about learning new things and about her hobbies. Staff reported that there were many opportunities for her to increase her decision-making capacity overall, except regarding her physical health, hygiene and body care (QOL). Although Cherisse did not have free access to the fridge in her home, she did have free access to her preferred items. She demonstrated choice and communicated her likes and preferences very clearly (Assessor Questionnaire). Her overall cognitive capacity for daily decision making was considered by staff to be consistently poor, requiring cueing and supervision at all times (Inter-RAI ID).

During the second visit, staff observed that Cherisse's choice-making abilities had been increasing as her verbal repertoire had also been increasing. Therefore she was able to exercise and communicate her decisions more freely and clearly (Frontline Staff questionnaire, section D & E) for example, she would make the choice and communicate her desire to go for a van ride.

During the third visit, Cherisse appeared to make very few, if any, decisions for herself and there appeared to be few opportunities for her to make those decisions on her own as compared to the first two visits. Overall she appeared to exert the most choice-making ability as related to who she spent her time with, such as family and friends. Cherisse's independent choices were focused around choosing to lie down on the living room couch for most of the day if she was not encouraged to get up and moving, but she could be very purposeful when her mind was set. She was also very capable of making the choice between two items if given the opportunity (Assessor questionnaire).

Overall, staff reported an increase in Cherisse's choice-making abilities and opportunities. For example, if you held up two pieces of clothing, she would choose the one she wanted. She would also go to her closet and change, by her own choice. Moreover, if the radio was on in her room and she really fancied a particular song, she would choose to go into her room and listen to the song. Cherisse also demonstrated decision-making in regards to the option of whether to go out or stay home on the couch. She also made food choices about which she was very particular. In short, staff observed specific increases in decision-making in the areas of music, food, outings and clothing (Frontline Staff Interview, section E).

Adaptive/ maladaptive functioning.

During the first visit, Cherisse was clean, groomed and dressed appropriately during the assessment period, but did not engage in any physical activity. She appeared to behave

confidently and was able to clearly communicate her likes and dislikes (Assessor questionnaire). She was considered to have a consistent positive outlook and found meaning in day-to-day life. In terms of communication abilities, her expressive and receptive language skills were considered to be limited to making concrete requests and being responsive to simple direct communication respectively. In terms of her functional status, she was dependent on staff for performance of routine activities around the home. She was capable of managing her finances with maximal assistance from staff and only needed limited supervision in terms of her performance and capacity to perform housework. With respect to activities of daily living, she was dependent on staff support for her bathing and hygiene routine and toileting. She required extensive assistance for dressing her upper and lower body, and no assistance for walking and navigating the home (Inter-RAI ID).

During the second visit, the data revealed that Cherisse was able to turn her head toward a speaker when her name was called. Her verbal repertoire included at least 10 words that were easily understood including cup, bed, and van ride. She was able to find her way to a specified room when told to go (SIB-R). While Cherisse appeared to be clean and appropriately groomed, her dressing was layered such that she had shorts layered over her pants and she had multiple layers of shirts on all at once. She displayed some emotional discomfort, evidenced by sporadic bouts of crying, yelling, hitting, controlled dropping and throwing objects around the house. The majority of the assessment period was spent lying on the couch.

After the initial transition, it was estimated that Cherisse took about one year to establish her routines in her home. She had developed strong relationships with certain staff with whom she initiated hugs. Although she rarely used first names, she had begun calling a particular staff by name, and more so when she was upset. She also began to associate certain

songs with certain staff, which she would sing when the particular staff was present. In contrast, Cherisse had not developed any strong relationships with her peers (Assessor Questionnaire).

During the third visit, Cherisse was able to make sounds or gestures to get attention. She speaks in three to four word sentences and was very capable of following a conversation and imitating others. She was able to put her shoes on the correct feet and had a sense of fire awareness and safety (SIB-R). Cherisse was somewhat physically active. However, due to tiring easily, opportunities for exercise were naturally limited. She identified certain songs and phrases with particular staff. With respect to her peers, she knew who was who, but did not attach the same importance to her peers as she did to staff. She was very observant in terms of following the activities of her home and loved to look out the window to see the country scenery (Frontline Staff Interview).

Based on data from the first visit, Cherisse engaged in some self-injurious behaviors, namely head and body hitting. Both of these behaviors occurred monthly. Head hitting was severe and body hitting was considered to be moderately severe. She also engaged in body rolling in the flexion position, which also occurred monthly and was considered to be severe. Cherisse engaged in aggressive and destructive behaviors such as hitting, kicking, pushing and grabbing others. Furthermore, she engaged in disruptive behaviors, such as daily screaming which was considered to be severe, in addition to throwing objects, public undressing, and crying which occurred monthly and were moderately severe (BPI). The most prominent behavioral problems being managed by Cherisse included screaming, foot stomping, undressing, controlled falls, summersaults and targeted aggression towards others (CMSI, section D). Additionally, she contended with mood related issues such as labile affect, blunt affect, irritability, making negative statements, decreased energy and sad worried

expressions. Some anxiety related concerns included repetitive anxious complaints and expressions of unrealistic fears and outbursts of anger (Inter-RAI ID).

During the second visit, Cherisse engaged in multiple forms of self-injurious behaviors including head and body hitting and foot stomping, all of which occurred daily with moderate severity. She also engaged in vomiting, rumination and self-pinching monthly, with slight severity. She was known to insert her fingers in her body cavities weekly; with slight severity and finally, Cherisse had "controlled falls" weekly, which were considered to be most severe.

Cherisse also engaged in aggressive behaviors such as throwing objects and feces smearing monthly, with moderate severity. She demonstrated bully behavior such as pushing, hitting, grabbing and kicking others ranging from daily to weekly and ranging from moderately severe to very severe. Cherisse's disruptive behavior profile included public stripping and crying which occurred daily and weekly, with moderate severity (BPI and SIB-R). The most prominent behavioral problems included screaming, kicking, hitting, controlled falling, foot stomping and stripping (CMSI). Staff also reported an increased use of PRNs (as needed medications) due to an increase in the duration and intensity of behaviors. In the previous three months, nothing had helped her to deescalate behaviors such as head hitting on floors and walls, screaming and stripping (Behavior/Medical Status). In terms of her moods and behavior, Cherisse dealt with flat and labile affect, irritability, hyper-arousal, and expressions of guilt, negative statements, decreased energy, crying and sad facial expressions. She also contended with anxiety related issues such as anxious repetitive complaints, compulsive behaviors and episodes of panic, in addition to expressions of a lack of pleasure in life, withdrawal from activities of interest, lack of motivation and reduced social interaction. Furthermore, she had repetitive health complaints and verbalizations, persistent anger with

self and others. She was also considered to be physically and verbally abusive, socially inappropriate, including inappropriate sexual behavior. She also resisted care (Inter-RAI ID).

During the third visit, Cherisse's maladaptive behaviors in general were fairly consistent, including self-injurious, aggressive, and disruptive behaviors in terms of their severity and intensity. Similarly, her mood related behaviors remained consistent.

Cross Participant Analysis

Social inclusion.

It appeared that John's opportunities for social inclusion had increased across the observation times. For the first year that John moved into his home, he would ask to go back to the ward approximately once or twice a month. By the time of the final visit, it was clear that friends and family had become increasingly important to John as was evidenced by regular contact with family members as well as closeness to another peer, as described by staff. John also increased his ability to participate within the social setting. For example, he was able to recognize and offer help to peers as well as staying on topic during sustained conversations. John had developed a rapport with one of his roommates in particular that had given rise to such altruistic behaviors as holding doors open and escorting one another to bed at night. John also showed observable gains in his participation in the community, in contrast to our initial meeting. He participated in Special Olympics baseball, basketball and bowling, attended bingo and cooking classes and maintained membership and participation at the local gym. He was also seeking gainful employment.

As of the last visit, staff and family members alike felt that the rural setting of his home presented a challenge to his ability to engage in more social opportunities. This was because

the nature of the rural setting was such that there were no sidewalks or public transit. Thus the ability to go outside for a walk was limited, particularly during the winter. Staff and family members felt that ideally, John would have more opportunities to foster a deeper sense of social inclusion if he resided in the city and had access to public transportation and clear and safe side walks for walking outdoors, which was one of John's consistent and most preferred activities.

June's opportunities for social inclusion had increased considerably post deinstitutionalization. She went from participating in a day program in the institution to participating in numerous social and community based activities in the community, even so far as to be nominated as the queen of the local chapter of her social club. This demonstrated that June interacted meaningfully in social settings and valued the opportunities. In general, the scope of June's experiences was limited by biomedical exceptions but she communicated her likes and dislikes primarily through the use of eye contact and was well liked and accepted by peers in her home. Specific to the data collection time period, it appeared that the opportunities for social inclusion had increased slightly, particularly referring to the different types of community activities that June was involved in, which was in line with staff's goal of expanding June's social circle by exposing her to more opportunities for engagement.

Sonny was quite actively involved in many hobbies and social activities within the institution. The localization of activities within the institutional setting was quite convenient for Sonny due to ease of accessibility. Comparatively, it appeared that Sonny's opportunities for social inclusion had decreased post deinstitutionalization. More specific to the post deinstitutionalized time period, it appeared that over the observation period Sonny had participated in more novel experiences than ever before, such as pet therapy and drumming circle. He had also reconnected with a friend from the institution, which he appeared to value

immensely. Otherwise, his post deinstitutionalized relocation actually restricted his community access to due lack of a consistent and dependable form of transportation. This was confounded by the fact that he was not socially included within his larger residential setting, which was also markedly different from his life within the institution, where his access has been unrestricted on the ward. In short, although his opportunities for social inclusion decreased post deinstitutionalization, staff endeavored to expose him to novel experiences as some form of compensation for his exclusion from the social setting. Moreover, staff strove to offer individualized attention during times when his suite mates were attending social activities within the larger residential setting. Since his transition to community living, Sonny also experienced negative reactions from community members, which he was generally protected from within the institution due to being confined to the institutional premises.

Overall, it appeared that Cherisse's opportunities for social inclusion had not increased post deinstitutionalization. She was still involved in the same activities that she was involved in within the institution. One of the most obvious differences was that she had one-to-one staffing in the community in order to support her participation in social activities of long standing interest, where she did not have one-to-one staff in the institution. Furthermore, her social inclusion opportunities within the community were limited by the rural location of her home, the lack of community members within close proximity and, finally, by the lack of a fenced-in property which prevents her from going outside to enjoy the rural scenery or even take a walk. In addition, Cherisse's formal opportunities for social inclusion had decreased as well because she was not involved in any day programming, but instead her opportunities for social inclusion were directly contingent on good behavior.

Choice making/autonomy.

In general, John had increased in his ability to exercise his decision-making abilities. This change was evident across the observation period. Overall, his cognitive skills for daily decision making increased steadily across time. In the institution, he was described as being severely impaired, requiring staff to make all of his decisions but post deinstitutionalization and across the observation period, this ability steadily increased to the point where John's daily decision making ability was regarded as only having some difficulty in new situations. In other words, his choice-making was mostly autonomous but sometimes modified where necessary.

Furthermore, his repertoire of things that he made decisions about also seemed to be continually expanding. In the past, institutional staff described John as a quiet introvert who did not make decisions for himself. Post deinstitutionalization, he began making quite a few decisions about his leisure activities, and this had since expanded to include his body care and hygiene, food choices, meal choices including what to drink and what to have for dessert and snacks daily, what time to wake and go to sleep, daily clothing choices as well as sporadic changes during the day, the choice of whether and where to go in the community and what to buy when in the community. Finally, John's increased choice-making ability was clearly evident in that he showed preference for certain staff.

In terms of June's choice making and how it changed over time, it appeared that relative to pre deinstitutionalization, her decision making opportunities had increased from never making decisions, to making some decisions regarding choice of friends and food preferences. Within the examination period, it appeared that June's opportunities for choice-making increased slightly with respect to showing a preference for staff or choosing to eat for

certain preferred staff. Otherwise, there were no discernible changes in her choice-making ability, in some part due to her biomedical profile.

Sonny's choice-making capacity increased since moving into the community, as compared to his life in the institution during which time he made no decision for himself. Post deinstitutionalization, Sonny's decision-making capacity was consistently described as more independent. He also had developed the ability to demonstrate increased choice-making with regards to taking more initiative to help with household chores and errands. However, over the final observation time, staff rated his decision making capacity as worse than during the previous two observation points.

Cherisse demonstrated clear gains in her choice-making ability since moving to the community. Pre deinstitutionalization, she was described as not making any choices for herself. However, over the course of the observation period, it became apparent that her decision making capacity was increasing. Staff observed that this increase also coincided with an increase in her verbal repertoire. By the time of the final visit, she made choices regarding how she spent her day whether it was indoors, partaking in hobbies of long-standing interest, or outdoors going into the community. She also exhibited large gains in her decision making capacity with respect to clothing and food choices, the choice of what room to spend time in at home and other decisions related to preferred staff. Staff had begun to offer her more forced choices upon observing that she was increasing in her capacity to make self-directed choices.

Adaptive/maladaptive functioning.

It appeared that John's adaptive profile increased post deinstitutionalization. Although the initial year following the transition was described as causing John anxiety because he appeared to miss his peers in the institution and would often ask to be taken back to the ward, John was described as being able to find meaning in life and having a positive outlook. Staff

observed this valuation for life as John began to adjust to his new home and he began to invest more in the welfare of his housemates. During this time, he began to behave more confidently and also began helping his housemates more regularly. John's communication abilities also increased over time. Staff observed that, although John's verbal expression was generally limited to making concrete requests, he did have the ability to make himself understood with prompting. He also had no issues with language comprehension.

With respect to his functional status by the time of the last observation period, John was only fully dependent on staff to manage his medications and finances. He only required supervision from staff regarding bathing and personal hygiene and dressed himself completely independently. During general household activities, such as chores and meal preparation, he required only oversight and cueing, which was an overall vast improvement from his institutional assessment, which was described as being fully dependent on staff for everything.

In reference to John's maladaptive behaviors, he engaged in multiple forms of self-injurious behaviors in the institution and this was also observed during the initial observation period. This drastically reduced to a few behaviors (specifically fewer than 3) that occurred less than once a month and that staff considered to be slightly intrusive, as compared to more severely damaging behaviors that were absent from his later profile. By the last visit John was not engaging in any aggressive behaviors as compared to multiple forms of aggression described in the institutional records and during the first visit. With respect to disruptive behaviors, it appeared that John's behavior profile remained consistent across time. He continued to engage in yelling and screaming behavior as well as property destruction, with the same severity and frequency.

Finally, John's general mood and behavior profile steadily increased over time, particularly during the final observation period. During the initial observation, John was regarded as having very few anxiety related issues and behavioral concerns around verbal abuse in particular. During subsequent observation times his profile kept expanding to include mood and behavioral symptoms, anxiety and negative symptoms.

June's adaptive behaviors increased post deinstitutionalization as compared to while living in the institution. Pre deinstitutionalization, she was described as lacking the ability to understand others or make herself understood. Post deinstitutionalization, it was obvious that she made herself understood through the use of eye contact, smiling and facial expressions in general. Her receptive language had also increased quite a lot and demonstrated that she understood most of the message during communication with others, which was evidenced by her level of engagement in group encounters. She oriented to the novel face in the room as was evidenced when she stared at research assistants who observed her in her bedroom. Post deinstitutionalization, she was described as finding meaning in life, which was more positive than the pre deinstitutionalization description. Overall, her level of physical activity was stable post deinstitutionalization.

Overall, June's maladaptive profile had been stable across time, both pre and post deinstitutionalization. She contended with few consistent mood related behaviors that appeared to be fairly consistent.

Sonny's adaptive behaviors increased post deinstitutionalization. He was able to account for certain aspects of his activities of daily living, which was non-existent before deinstitutionalization where staff accounted for all of his activities of daily living. Otherwise, his adaptive behaviors had been consistent across time.

Due in part to his prevailing biomedical profile, Sonny's maladaptive behavior profile was fairly consistent across the time period pre and post deinstitutionalization.

Cherisse's adaptive behaviors appeared to have increased in certain areas since deinstitutionalization. In general, it seems that her overall outlook on life had increased post deinstitutionalization to the point where she considered her life and experiences as valuable. More specifically, staff reported that Cherisse's communication abilities had increased since the transition into the community, which was supported by the fact that she was able to orient and follow a conversation, a skill that was not apparent or noteworthy in the institution. Due to the natural progression of age, Cherisse was limited in her ability to engage in walking as a healthy form of exercise due to tiring easily. On another hand, Cherisse did not appear to be free from emotional problems as was evidenced by sporadic bouts of high-pitched screaming, stripping and other maladaptive behaviors.

With respect changes in maladaptive behaviors, it appeared that Cherisse's maladaptive behavior profile had increased since her deinstitutionalization. She was described as having few maladaptive behaviors, including self-injurious behavior (SIB) in the form of body rolling. Although this was considered an SIB because of the potential for harm, Cherisse had never been injured from her body rolling and was uniquely flexible. Thus, specific to this individual the behavior did not present any harm, but did have the potential to in theory.

Post deinstitutionalization, Cherisse had acquired multiple forms of self-injurious, aggressive and disruptive behaviors. Her self-injurious and aggressive behaviors seemed to have peaked during the second observation period, which coincided with some drastic medication changes that were implemented and enforced by her family advocates. However by the third observation period Cherisse appeared to manage many more maladaptive

behaviors than she did while living in the institution, although she was managing fewer than during the second observation period, which represented a peak period of maladaptive behaviors.

DISCUSSION

This research may be valuable to individuals who need this transitional assistance from institutional to community living, and will make a real difference in the lives of persons who are currently disproportionately underrepresented, and often times disadvantaged, in our society. Accordingly, it was important to consider what were the factors that were associated with transitional success or lack thereof for each of these case studies. For example, what aspects within their environment may have contributed to increases or decreases in their overall quality of life, as was evidenced by gains or losses in social inclusion, choice-making and adaptive behaviors. In short, what were the positive and negative trends within and across the case studies?

Implications for the research questions

Social Inclusion: How have the opportunities for social inclusion changed for the individuals, pre and post deinstitutionalization?

One of the contributing factors to the observable gains in social inclusion that were evident for John and June may have been the fact that their agencies utilized an individualized planning approach and support staff transitioned from the institution with them. This may have contributed to their continuity of care because the staff members were already familiar with them as well as their preferences. It may be inferred that this made it less difficult for the staff to make connections within their respective communities. On the other hand, Sonny and Cherisse moved into residences where the individuals, staff and residents alike were all meeting for the first time. It follows that the staff would have less knowledge of their preferences, especially in cases where the residents themselves were not able to clearly communicate their preferences.

Consistent with the literature, social inclusion was partially dependent on the functional abilities of the individual (Thorn, Pittman, Myers & Slaughter, 2009). This was true for John, whose functional status includes a range of abilities. On the other hand, June was very limited in her functional abilities due to her bio medical diagnosis, but she was still socially included in multiple forms. In this case, it appears again that the staff familiarity served as a buffer against social exclusion. According to McConkey and Collins (2010), staff members using a person centered planning approach tended to place a high priority on issues related to the social inclusion of the individuals being supported.

Also consistent with the literature, some individuals, such as Sonny and Cherisse, experienced less interaction with neighbors or others in their larger communities, as compared to non-disabled individuals (McConkey & Collins, 2010). This may directly affect their opportunities to create larger social networks. This fact was supported by research that had observed that group homes embedded in the community as a means of community integration may have insufficient support structures to ensure social inclusion (Wituk, Pearson, Bomhoff, Hinde & Meissen, 2007). In both of these cases, the residential dynamics contributed to challenges that hindered these individuals' opportunities for social inclusion, such as rural isolation and lack of a readily available form of transportation.

Choice-Making and Autonomy: What aspects of choice-making / autonomy changed for the individuals, pre and post deinstitutionalization?

In general, all of the four persons described in these cases demonstrated clear signs of increased choice-making. In line with the current literature, varying levels of communication and overall functional ability may have contributed to the individual differences that made each case unique. For example, John's autonomy increased partly due to staff's familiarity

with him, which allowed them to offer him choices that reflected his personal preferences. As noted by Stancliffe and Avery (1997), an increase in the ability to make choices that affects one's life contributes to feelings of self-efficacy and a concurrent decrease in learned helplessness, which leads to overall increases in the quality of the daily lived experience.

The increases in choice-making/autonomy with respect to June, although similar to that of John, support the conclusion that individuals who were not verbal could also achieve higher levels of autonomy, through the use of gestures and eye contact (Neely-Barnes, Marcenko & Weber, 2008), which in June's case was a very prominent communicative feature in her capacity to make choices as independently as possible.

Sonny's case exemplifies a situation where the basic living arrangements may in fact hinder his ability to take advantage of the full range of choices that may otherwise have been available to him. In short, it may well be the case that offering Sonny less inhibited choice capacity could put staff members and fellow residents at risk (Antaki, Finlay, Walton & Pate, 2008).

With respect to Cherisse, although she did make decisions, they were mostly regarding what to wear, eat, what music to listen to and watch on TV, which were important for the quality of Cherisse's lived experience, as indicated by staff. This was contrary to research by Heller, Miller & Factor (1999), which states that these issues may not in fact have an impact on the richness of the daily lived experience. Although they may not be big choices, they were nonetheless important choices for Cherisse to make for herself.

Adaptive and Maladaptive Behavior:

How has adaptive behavior changed for the individuals, pre and post deinstitutionalization?

Consistent with the literature, increased adaptive behavior was proportionally related to increases in social inclusion and choice-making (Heller, Miller and Factor, 1999). This pattern was generally evident across the cases chosen for this study. In John's case, it was evident that the staff had worked with John to gain a skill set through volunteering and possible work placements. According to the research, this emphasis on actualizing of functional skills had a direct impact on subjective feelings of independence (Molony & Taplin, 1990), which in John's case was evident in his increased initiative taking with his peers. However, in Cherisse's case, it was clear that one of the factors that affected her continuous adaptive gains was the inconsistency within her support system, as identified by Dagman, Ruddick and Jones (1998) to hinder sustained adaptive gains. The inconsistency in her support system may have been due to inconsistency between family, medical practitioners and staff systems that did not always agree on a common approach to supporting Cherisse. In Sonny's case, it was clear that the adaptive benefits that he experienced as a result of the transition into community residence did not moderate the relationship with his maladaptive behaviors. In general, it appeared that biomedical issues affected Sonny's and Cherisse's adaptive gains, which can be prevalent in adults with intellectual disabilities (Heller, 2004). In contrast, John and June appear to have existing medical issues that appeared to be more stable in their management.

How have the maladaptive behaviors changed for the individuals, pre and post deinstitutionalization?

Within the literature, maladaptive behaviors consistently predicted impermanent social inclusion (Benson & Brooks, 2008; Blacher & McIntyre, 2006). In the cases of Cherisse and Sonny, this appears to be consistent. In both cases, existing maladaptive behaviors may have been the primary cause of Sonny's social ostracism as well as Cherisse's inability to be as

socially included as she and her support team may have desired for her. For example, Cherisse's public disrobing may be one of the contributing factors to her limited opportunities for social inclusion. On the other hand, John who had demonstrated consistent decreases in his general maladaptive profile since his relocation into the community had experienced clear gains in social, adaptive and choice-making, which was also consistent with the literature. How do social inclusion, choice-making, adaptive behavior and maladaptive behavior interact within each individual to influence the quality of their lived experience?

With respect to John, one of the predicators of his successful transition to community living was unarguably the fact that the staff transitioned with him from the institution. Thus, they were familiar with him and he was familiar with them, which could be considered to be an advantage towards a smooth transition based on the level of familiarity that had already been fostered. Based on the positive rapport John had with his staff, they were able to advocate for his participation in various activities that they knew would interest him, and did not have any lag period focused around getting to know the individual well enough to satisfactorily represent their thoughts and desires, considering that the majority of John's speech was echolalic. Clear gains with regards to social inclusion can be directly attributed to the fact that staff was already familiar enough with John to be able to implement a graduated plan to challenge John's capabilities enough to eventually introduce him to employment opportunities. John also demonstrated a clear decline in self injurious and aggressive behaviors post deinstitutionalization, which may be attributed to feeling less threatened within his immediate living environment and, more specifically, feeling more positive about his life and taking more meaning out of his life. This fact can be supported by the variety and number of activities that John was engaged in, which provide ample opportunity to leave one feeling integrated in their residential community.

In terms of the increase in his mood and behavior profile, it may be inferred that this could be a biomedical issue that required a thorough medical and physical review as the basis for a comprehensive biomedical investigation and analysis. The goal of this would have been to assess if this behavior could possibly be managed through medical intervention, within a biopsychosocial framework of support. Another alternative to consider may be to consult with a behavior therapist in order to investigate what the reinforcers were for the existing behaviors. This information could be used to introduce replacement behaviors that were more adaptive and prosocial.

In terms of June, biomedical issues tend to set the limits within which she exists and it was clear from her counter story that it was important for her successful transition that she was familiar with the staff who transitioned with her into her community residence. It appears that this factor was an advantage because it allowed the staff to contribute their ideas on behalf of June in terms of her likes and dislikes, which contributed to how quickly she assimilated into her home. Another important factor that seemed apparent was that June's family also contributed their input into how best to approach the transition to ensure the greatest chances of a successful transition for June. The most advantage was evidenced in her increased social inclusivity. On account of the rapport she already had built with staff, they were able to expose and engage June to numerous activities that she clearly finds value in and, on the other hand, if the staff were not familiar with June, it would have been more difficult to know what activities she would find interesting, engaging and meaningful. It was arguable that this style of individualized planning that was supported by an understructure of patient – client familiarity could have contributed to her fairly smooth transition and how well integrated within her community June is. In addition to clear social inclusion gains, June demonstrated some gains in her choice-making ability that can also be attributed to the

already present rapport she had with her staff. This was reported to be because she already had developed a comfort level with these people which may have allowed her to feel confident enough to assert her will. Also, the staff knew her well enough to be sufficiently sensitive to gage her responses, through eye contact, which was her method of communicating. This obviously takes a fine awareness of the individual in question. In relation to these issues, the demonstrated adaptive gains attested to the influence of her familiarity with the staff. The staff members were familiar enough with June to have a basis for conversation, which enabled them to include her and draw her into group encounters, which she appeared to enjoy, even though her contribution may not have been overt or even obvious. Those who know her knew what subtleties to look for as evidence of her participation in group and social encounters.

In Sonny's case, his decline in social inclusion post deinstitutionalization could be attributed partially to the issues of social exclusion within his larger residential setting as well as a lack of specific infrastructure necessary to support an individual with the repertoire of challenges that Sonny presents with. It was important to also point out that these restrictions, such as a lack of consistent transportation fall outside of the realm of control of the staff who directly supported him. The issue was more related to the fact that as Sonny was aging, the agency responsible for his care had identified that his needs had begun to fall outside of their scope of services and would be more appropriately supported provided by long term care approach. Typically it would make sense to progress from one service sector to the other as needs change and evolve, but that did not speak to the organizational systems that must align for the transition to be smooth. In this case, the agency could not just transfer him to a more appropriate floor within the larger nursing home complex in response to changing needs, because even though they were all housed on the same premises, they were funded by

different ministries, which confounds what would appear to be a convenient and simple solution to meeting Sonny's felt needs. Therefore, although the agency was committed to offering Sonny a quality of experience that was rich and full of novel experiences, the fact was that they simply did not have system supports in place to address some of his needs, try as they may. Sonny and his staff may have been frustrated when the services that he needed were housed on the same premises where he lives but were not accessible to him due to organizational systems that were outside of their control. Sonny's choice and adaptive behaviors increased post deinstitutionalization, which could be attributed to staff's persistence with offering him opportunities to empower him with the capacity to make realistic choices and also by virtue of having more opportunities to engage and take active control of aspects of his life. Sonny also demonstrated adaptive increases and some stability with respect to his maladaptive behaviors.

Within a previous case study, staff familiarity with the residents facilitated a smooth transition and enabled staff to expediently reconnect the clients within their new communities. In this case, it appears that the staff and residents were all new. On one hand, this was a positive thing because everyone was new and thus there were no sociocultural norms or expectations that were implied from a previous knowledge of one another. Instead, it was considered to be a fresh start for everyone free from biases of any form. On the other hand, if there had been some level of familiarity between Sonny and the staff, it may have been clear from the onset that he would have been more appropriately placed in a high energy environment with plenty of stimulation within his day and more opportunities to integrate into his community to address his feelings of social inclusion. This case also illustrated the fact that it was important to ensure that a long term plan was generated for clients as a means

of planning for and ensuring that the funding was adequate to facilitate the individualized plan.

It appeared that Cherisse's opportunities for social inclusion and other opportunities in general were affected by what seemed to be a need for a comprehensive biomedical assessment. Some of the data collected in this case revealed that during some of the times when her maladaptive behaviors increased coincided with times of medication changes that were implemented by her team of practitioners at the request of her decision makers. The point was that if decisions were left to the staff and Cherisse's team of practitioners they would have not advocated for some of the medication changes that were implemented on Cherisse's behalf. This issue only highlights the importance of cohesion and a clear and focal goal within the individualized care plan in order to at least offer continuity of care to the individual. In cases where the decision makers and direct care team are not clear and in line with their ideas of what the felt need is, there is a very strong argument to be made that the individual at the center of this discrepancy suffers the most.

Another issue that affected Cherisse's ability to receive thorough and clear medical attention after her transition into the community was the fact that the agency that supports her had a difficult time sourcing medical services for their clients because the medical professionals in the community, including occupational and physiotherapists, speech and language therapists, general and specialized practitioners were hesitant to add to their case loads. This was in stark contrast to the institutions, which employed teams of medical professionals that specifically serviced that group of clients, in which case they had timely and consistent medical attention and access to a team of specialists which offered the clients continuity of care for many years. Unfortunately, from the data collected it appeared that the medical community was not consistently prepared for this transition and consequently, newly

deinstitutionalized residents suffered as a result. In essence she lost the established rapport and the continuity of care that was critical to meeting Cherisse's felt needs as a primary and focal responsibility. Practically, this means that Cherisse did not have a team of specialists at her disposal, but only consults with some professionals and not as often as she needed or provided as if she were their consistent patient.

One possible solution to this issue could be to provide information and education for medical professionals in advance of future deinstitutionalization endeavors. In other words, there is a need to conduct training courses, seminars, small focus groups and advocacy programs that empower medical professionals with the tools they need to adequately support an individual with an intellectual disability. Also it may be important to offer financial assistance in order to enable medical professionals to get the ongoing training they need to be informed about current and evidence based research.

Another possible solution is to open government supported multidisciplinary services such as a clinic system that could offer general and specialized practitioners such as psychologists, social and community workers, occupational, recreational and physiotherapists all within one site so that clients could patronize services in their residential area. The primary purpose of such biopsychosocial teams would be to empower individuals with intellectual disabilities with greater access to medical and health services.

With respect to this specific case study, it could be inferred that Cherisse's adaptive and maladaptive profile would be directly affected by a thorough medical assessment and evaluation, and continues to be affected by medical fluctuations and lack of a clear behavior assessment, which can only be achieved once her medical profile is stable.

Strengths and Limitations

One of the major strengths of this study was that it contributed to the dearth of research within Ontario about the effects of deinstitutionalization on the people who have been most directly and quintessentially affected by the relocation.

Another major strength of this study was related to its contribution to the field of Applied Disability Studies in terms of postulating a framework that may be applied to the general population, as well as other jurisdictions in their journey towards deinstitutionalization. It was also beneficial in terms of generating a set of themes that can be useful for future deinstitutionalization from which other jurisdictions may be able to benefit.

In comparison to other western countries, such as the UK, USA and Australia, there has been very little research in Canada and Ontario in particular, on the impact of deinstitutionalization. This research involved the use of discrete-trial observations of outcome behaviors in individuals with intellectual disabilities who had been recently deinstitutionalized. This was significant because studies of this specific nature have not been conducted previously in Ontario.

On another hand, one of the major limitations to this study was that although multiple forms of assessment methods were used, including questionnaires, direct observation and multiple responders during the post deinstitutionalization data collection phase, the Inter-RAI ID was the only assessment method administered pre deinstitutionalization. Although this study was originally designed to include consistent assessment methods pre and post deinstitutionalization, unanticipated delays in acquiring ethical consent from the multiple sources necessary to meet confidentiality standards made it such that informed consent was finalized after the individuals had already been deinstitutionalized. Therefore, pre deinstitutionalization data in this case relied upon a thorough file review and the Inter-RAI ID,

which was administered consistently across the data time points. The study originally had been designed to administer a consistent repertoire of assessments across all data points. In reality, the execution of the study being influenced by real life factors that were uncontrollable, was only able to apply a consistent repertoire of assessments to the post deinstitutionalization data collection time points. This issue compromises the validity of the results somewhat and future studies can correct this issue by administering a consistent battery of pre and post measures.

Another issue initially thought to be a limitation was the staff turnover rates and the reality that at each of the three data points different staff could be completing the assessment, some of which were subjective in nature and therefore required staff to rely on their biased opinions primarily. It was initially thought that there may be some advantage to conducting such assessments with one staff's consistent opinion across time, but at each subsequent visit, the reality of residential care services was that there was an element of staff turnover. Thus, meeting different staff and conducting the assessments with them revealed richness within the data that could not otherwise have been extracted from a single source.

Another natural limitation of this study was the fact that all of the participants for this qualitative case study analysis were non-verbal and generally within a similar range of functioning. Future studies may endeavor to collaborate with participants who have a wider range of functioning and with various levels of communication ability. It would be ideal to have participants who represent all ranges of functioning and communication ability because having the ability to layer self-report measures over other-report measures would lend to the richness of the data. For this study, the individuals who responded to the invitation to participate in the study, and who fit all the inclusion criteria, were all within a similar range of functioning and were all nonverbal and as such, the process of data collection did not include

the resident in any direct way. Finally the generalizability of the results was impeded by the small sample size. Future studies may endeavor to use a larger sample size, which will lend power to the study in general and allow for generalizability of the results to real life settings.

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Appendices

Appendix A

INVITATION TO PARTICIPATE / RECRUITMENT LETTERS

This letter will be distributed BY THE MINISTRY AND THE RESEARCHER

Dear Family Member, Guardian, or Trustee,

As the ministry moves into the final leg of its 4-year plan for the full closure of the three remaining facilities, a study will be carried out to independently assess the experience of residents, their families and their friends. This will provide important information about the outcomes of deinstitutionalization

The study:

- supports the government's commitment to community living and to transparency with respect to the Facilities Initiative
- is part of a process of continual learning and ongoing quality assurance in the sector
- will identify factors related to successful community living for adults with a developmental disability
- will inform and support the development of evidence-based policies and programs in the transformation of Developmental Services
- will help the ministry address any issues that may arise in a proactive way, based on evidence.

Attached you will find a letter that describes some ways that current and former residents of the facilities, their families, residential agencies and support staff can all participate in the study.

We ask that you please consider the different opportunities and that you contact the researchers directly if you have questions regarding the study or contact the Ministry if you have questions relating to an individual's past or pending move.

Thank you for your support of this historic study.

GENERAL AGREEMENT TO PARTICPATE IN THE FACILITY INITIATIVE EVALUATION

There are several different ways that people can be involved in this study. Kindly check off the parts that you might be interested in, and the researchers will send you specific information relating to that part of the study.

I would like to be contacted regarding:

❑ Opportunities for myself or a former resident to talk about our experiences in a focus group or personal interview.

❑ Opportunities to complete a survey designed to provide family members with an opportunity to share their experiences.

❑ Opportunities for the agency where a former resident now lives to give feedback on the person's transition to the community, and the services that they have and those that they still might need.

❑ Opportunities for the resident and their support staff to participate directly in a study to evaluate the outcomes of deinstitutionalization, and investigate the factors that predict different outcomes for individuals. These studies could include 2 or more visits with the person in the facility and/or community placement.

My name:_____

Address: _____

_____

Postal Code_____

Phone number:_____

Former or Current Resident's Name: _____

Date of Birth:_____

Current Place of Residence: _____

Contact Number: _____

Contact Person (if different from individual) _____

This letter will be distributed to the professional organizations BY THE Ministry of Community and Social Services AND THE RESEARCHERS.

Dear (agency executive directors, members of network of specialized care, regional placement facilitators,

As the ministry moves into the final leg of its 4-year plan for the full closure of the three remaining facilities, a study will be carried out to independently assess the experience of residents, their families and their friends. This will provide important information about the outcomes of deinstitutionalization

The study:

- supports the government's commitment to community living and to transparency with respect to the Facilities Initiative
- is part of a process of continual learning and ongoing quality assurance in the sector
- will identify factors related to successful community living for adults with a developmental disability
- will inform and support the development of evidence-based policies and programs in the transformation of Developmental Services
- will help the ministry address any issues that may arise in a proactive way, based on evidence.

Attached you will find a letter that describes some ways that current and former residents of the facilities, their families, residential agencies and support staff can all participate in the study.

We ask that you please consider the different opportunities and that you contact the researchers directly if you have questions regarding the study or contact the Ministry if you have questions relating to an individual's past or pending move.

Thank you for your support of this historic study.

GENERAL AGREEMENT TO PARTICIPATE IN THE FACILITY INITIATVES EVALUATION

There are several different ways that people can be involved in this study. Kindly check off the parts that you might be interested in, and the researchers will send you specific information relating to that part of the study.

I would like to be contacted regarding:

❑ Opportunities for myself or a former resident to talk about our experiences in a focus group or personal interview.

❑ Opportunities to complete a survey designed to provide family members with an opportunity to share their experiences.

❑ Opportunities for the agency where a former resident now lives to give feedback on the person's transition to the community, and the services that they have and those that they still might need.

❑ Opportunities for the resident and their support staff to participate directly in a study to evaluate the outcomes of deinstitutionalization, and investigate the factors that predict different outcomes for individuals. These studies could include 2 or more visits with the person in the facility and/or community placement.

My name:_____

Address: _____

_____

Postal Code_____

Phone number:_____

Former or Current Resident's Name: _____

Date of Birth:_____

Current Place of Residence: _____

Contact Number: _____

Contact Person (if different from individual) _____

Appendix B: Consents

Appendix B1

Frontline Staff Consent Form

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Case Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction
The family of the individual noted in the accompanying letter has given permission for this individual to be included in the Facility Initiative Research Evaluation as a CASE STUDY.

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research
The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year in transition. The individual noted in the attached letter has been selected to participate in this study and the designated consent source (family member) for the person has consented to his or her participation. This study will provide an important look at the impact that community living plays in the lives of the persons who have been moved from the facilities.

Description of the Research
If you agree to participate in this study, you will be asked to be interviewed to complete several measures regarding the wellbeing and quality of life of the individual and to

participate with our research assistants as they walk through the life of the individual. We will be asking you questions about the general wellbeing and functioning of the individual such as about the supports, health, activities and choices the person makes. The Research Assistants will be occasionally taking video samples of a typical day in the life of the individual. This is being done to see the types of activities and interactions the person participates in on a daily basis. *These tapes will be analyzed and maintained in a confidential location in our laboratories. No video tape of you will be ever used except for the purpose described above without your expressed permission.*

The Research Assistants will visit the person and meet with you 4 times throughout their first year during the course of your working day. Each visit will take approximately 2 days. Although the full two days will not be spent solely with you or the individual, we ask that you be available for the full two days although only 1 day cumulatively will likely require your time. The Research Assistants will be interviewing other individuals and will be reviewing the individual's file and reports.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information. Nothing that you tell us will be shared with anyone from your agency, unless you disclose a situation of neglect or abuse in which case we are compelled to report this.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. However each agency that participates and completes the requirements of the case study will receive an educational voucher. The voucher will be equal to a 50% discount on for four staff members of the organization to attend an educational event offered through the international dual diagnosis certificate programme (a $1500 value) summer 2009 or 10 or 15 free admissions to a training event offered by the centre for applied disability studies or a combination thereof. It is the agencies responsibility to decide how the voucher will be distributed.

Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law. For example, the researchers would have an obligation to report abuse should it be observed or reported during the course of our research.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the subject of projects and theses for students in the Masters of Applied Disability Studies programme.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on you or your agency. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #)
If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

For Frontline staff members

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose neither my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study. I will be given a signed copy of this consent form.

X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
X_____	_____	_____
Signature of Agency Staff Participant	Name (printed)	Date
_____	_____	_____
Signature of Investigator	Name (printed)	Date

Appendix B2

Agency administrative staff consent form

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Case Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction

The family of the individual noted in the accompanying letter has given permission for this individual to be included in the Facility Initiative Research Evaluation as a CASE STUDY.

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research

The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year in transition. The individual noted in the attached letter has been selected to participate in this study and the designated consent source (family member) for the person has consented to his or her participation. This study will provide an important look at the impact that community living plays in the lives of the persons who have been moved from the facilities.

Description of the Research

If you agree to participate in this study, you will be asked to be interviewed four times throughout the year. The purpose of the interviews is to maintain an ongoing story from many perspectives of the transition experience of the individual you have accepted into your agency. The questions we will ask you relate to your perspective on the process, for example how has the transition worked for the individual, the challenges that have been faced, the

availability of appropriate supports, and how well the planning process prepared the agency to support the individual.

The Research Assistants will visit your agency 4 times throughout their first year. Each visit will take approximately 2 days however we will interview you for only ½ hr to 1 hr out of that time. The Research Assistants will be interviewing other individuals, including staff while on duty, observing the individual, conducting random video taping of the person engaged in an array of activities, collecting data and reviewing the individual's file and reports. The time with your staff members will take approximately 1 day each visit however some of this time will be spent in observations with the staff member as they conduct their day.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. However each agency that participates and completes the requirements of the case study will receive an educational voucher. The voucher will be equal to a 50% discount on for four staff members of the organization to attend an educational event offered through the international dual diagnosis certificate programme (a $1500 value) summer 2009 or 10 or 15 free admissions to a training event offered by the centre for applied disability studies or a combination thereof.

Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law, such as in cases of suspected neglect or abuse. No information that you share with us will used in any way except as collective data; the Ministry will not be privy to your comments.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the topic projects or theses for students studying in the Masters of Applied Disability Studies.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on you or your agency. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #)
If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

For Agency Administrators

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study. I will be given a signed copy of this consent form.

I however have some exceptions to this consent: The exceptions are:

X_____	_____	_____
Signature of Agency Administrator	Name (printed)	Date
_____	_____	_____
Signature of Investigator	Name (printed)	Date

Appendix B3

Regional Facility Planners consent form

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Case Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction

The family of the individual noted in the accompanying letter has given permission for this individual to be included in the Facility Initiative Research Evaluation as a CASE STUDY.

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research

The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year in transition. The individual noted in the attached letter has been selected to participate in this study and the designated consent source (family member) for the person has consented to his or her participation. This study will provide an important look at the impact that community living plays in the lives of the persons who have been moved from the facilities.

Description of the Research

If you agree to participate in this study, you will be asked to be interviewed three times throughout the year. The purpose of the interviews is to maintain an ongoing story from many perspectives of the transition experience of the individual you have helped place in the community. Each interview will take approximately 1 hr out of your time. The questions we will ask are about the planning process for this individual and how well it has worked to create a smooth transition, Other questions might include the access to supports and

challenges in the transitional process. The Research Assistants will be interviewing other individuals, observing the individual, collecting data and reviewing the individual's file and reports.

We will attempt to find a time during your work day that is convenient for our interview.

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you feel uncomfortable, you can skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of the resident and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law. No information you share with us will be shared with the staff or agencies involved or with the Ministry unless you inform us of neglect or abuse, which we are obligated to report to the authorities.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released. We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the topic of projects or theses for students studying in the Applied Disability Programme.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no effect on you or your agency. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #)
If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

For Regional Facility Planners

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study. I will be given a signed copy of this consent form.

X_____	_____	_____
Signature of Regional Facility Planner	Name	Date
_____	_____	_____
Signature of Investigator	Name (printed)	Date

Appendix B4

Family Members Consent Form

Case Study: Facilities Initiative Review Evaluation

Lead Investigator and Contact Person for the Case Study: Dr. Dorothy Griffiths

Principal Investigators Drs. Dorothy Griffiths and Rosemary Condillac
Co-Investigators Drs. Frances Owen, Jan Frijters
Centre for Applied Disability Surveys
Brock University
Tel: 905-688-5550

Research Coordinator

Introduction

Before you agree to participate in this research study, it is important that you read and understand the following explanation of the study. It describes the purpose, procedures, benefits, and risks associated with the study. All research is voluntary. You are free to withdraw at any time without penalty. If you have questions after you read through this form, ask someone in your agency. You should not sign this form until you are sure you understand everything on it.

Purpose of the Research

The purpose of the survey study is to contribute to an evaluation of the impact of the facility initiative in Ontario by gathering information from people who are living through this experience. We will be conducting 10 intensive case studies of individuals throughout the course of their first year following the transition, your family member has been selected as one of those case studies. This study will provide an important look at the individual stories of those individuals who are affected by the Facility Initiative and the perspectives of their families.

Description of the Research

If you agree to participate in this study, you will be asked to be interviewed four times throughout the year (prior to placement, then 1, 3, 6 and 12 months following placement). The purpose of the interviews is to maintain an ongoing story from the perspective of the transition experience on your family member and you. You will be asked about the transitional process and how you feel your family member is doing and your satisfaction with the supports that are available. Each interview will take approximately ½ hr to 1 hr out of your time. The Research Assistants will also be interviewing other individuals, visiting your family member and speaking with him/her, collecting data and reviewing the individual's file and reports.

Some of the people moving from the facility to the community are able to answer questions about their experiences. We would like to ask the following questions of your family member if the person can and agrees to speak with us. The questions we would ask prior to the move are: Do you know where you are moving to? Have you visited the new place yet? Did you like it? Tell me about it. Have you met the people who will help you there? Did you like them? What do you think it will it be like? Do you think this is a good place to be going? How do you feel about leaving_____? What will change in your new place?

Then after the move and at 3,6,and 12 months we would revisit and ask: . *Would you like to talk to me for a little while about how you feel about your new home?* Will you show me around your house? Show me the things you like about this new place? What do you like about living here? Who are they people you like to be with? What do you get to do in the day? Is this a good way to spend your day? Are there some things you don't like as much about this place?

Potential Harms (Injury, Discomforts or Inconvenience):
If a question makes you or your family member feel uncomfortable, we can skip any question that you or your family member do not want to answer. There is potential risk to you if the confidentiality of the information you give us were to be lost. To protect your confidentiality, your information will be kept on a coded form that does not have your name or other identifying information. We will keep your name and that of your family member and other identifying information (such as name and date of birth) on a separate form. All information you give us will be kept in a secure research office, and only authorized research staff will have access to the information.

Potential Benefits:
There are no immediate benefits to you to participating in this study. You will not be paid for participating in this study. Moreover the true benefits of this study will come from sharing what we learn from you and from other participants that may help others who are involved in facilities closures around the world.

Confidentiality and Privacy:
Confidentiality will be respected and no information that discloses your identity will be released or published without consent, unless required by law, such as in cases of suspected abuse or neglect. The Ministry nor the agencies involved will not have access to your comments or those of your family member.

All information that identifies you or the individual be kept confidential and stored and locked in a secure place that only study personnel will have access to. In addition, electronic files that include identification information will be stored on a secure institutional network and will be password protected. It is important to understand that despite these protections being in place, experience in similar surveys indicates that there is the risk of unintentional release of information. The principal investigators will protect your records and keep all the information in your study file confidential to the greatest extent possible. The chance that this information will accidentally be given to someone else is small.

Publication of Results:
In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or identifying information will be released.

We will give you a summary of the results of our study after it is over if you tell us you want one.
The results will be published both by the Ministry of Community and Social Services and the Investigators of this research and will be the subject of projects and theses for students studying in the Masters of Applied Disability Studies.

Reimbursement:
You will not be paid for participating in this study.

Participation and Withdrawal:
Participation in research is voluntary. If you choose not to participate, you will not be affected in any way. Your decision to participate or not participate in this research study will have no negative effect on you or your family member. If you would like to withdraw from the study, you can do so at any time by contacting us by phone.

Study Contact Information:
If you have any questions about this research study, you may contact Dr. Dorothy Griffiths (905-688-5550 ext 4069, e-mail dgirffiths@brocku.ca) or Dr. Rosemary Condillac (905-688-5550 ext. 5671, e-mail: rcondillac@brocku.ca) (collect calls accepted).

This study has been reviewed and approved by the Brock Research Ethics Board. (File #)
If you have questions or concerns about this study you may call the investigators listed above or the Brock University Research Ethics Officer in the Office of Research Services at 905-688-5550 ext. 3035, email: reb@brocku.ca.

For Family MEMBERS

Case Study: Facility Initiative Research Evaluation

Consent to Participate in a Research Study:

Consent:
I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me and the individual being surveyed will be kept confidential and that no information will be released or printed that would disclose my personal identity nor that of the individual being surveyed without permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study and to have my family member as a participant in this study as discussed in the consent guidelines.

I will be given a signed copy of the consent form and guidelines.

X_____	_____	_____
Signature of Family	Name	Date
X _____	_____	_____
Signature of Investigator	Name (printed)	Date

Appendix C

CASE STUDY RECORD FORMS: HISTORY QUESTIONNAIRE DERIVED FROM ARCHIVES AND INTERVIEWS...

STEP 1: INTERVIEWING THE INDIVIDUAL AND SIGNIFICANT CAREGIVERS AND REIVEWING ALL DOCUMENTATION.

(Develop from review of the files including all past evaluations/ programs and fill in blanks with observations and staff interviews)

_____

Where has this person lived previously? Why were moves precipitated?

Create a timeline of the person's behavioral/psychiatric history and significant life events (Provide dates to show correlations).

Behavioral/Psychiatric History

/_____/_____/_____/_____/_____

Significant Life Events

/_____/_____/_____/_____/_____

STEP II: BIOMEDICAL/ PSYCHIATRIC ASPECTS

1. **Does the individual have any of the following:**

( ) known syndromes
( ) medical conditions
( ) ongoing medical problems
( ) psychiatric diagnoses

Specify any and all of the above:

2. **What is the health status of the person and has the health of the individual changed recently? How? When?**

3. **Has the person been hospitalized within the past 5 years and if so for what reason?**

4. **Does the person experience problems in any of the following:**

( ) activity level or energy_____
( ) socialization_____
( ) interest in previous activities____
( ) eating_____ Note any special dietary needs_____

( ) skills_____
( ) bowel or bladder_____
( ) irritability_____
( )sleep_____ Describe

If so, please describe when did the problem start and how?

5. **Does the behavior:**

( ) come out of the blue
( ) show no predictable pattern
( ) occur with hallucinations or delusions
( ) occur with repetitive verbal behavior
( ) occur with specific repetitive physical behavior

If so, please describe:

6. List present medications/ dosages and reason for prescription? Have medications for the individual changed recently? How and when?

7. Could the medications in any way contribute in isolation or in combination to the any problems the person may be experiencing? If so how?

8. Develop a timeline of the medical/ medication history to the behavioral/psychiatric changes (provide dates to show correlations)

Medical History/Medication Changes

/_____/_____/_____/_____/__

Behavioral/Psychiatric Changes

/_____/_____/_____/_____/__

9. What medical/psychiatric considerations must be taken into account when the person is transferred? (support/ specialists/ personal vulnerabilities/ setting events/ staff training etc.)

STEP III: PSYCHOLOGICAL ASPECTS

1. **Describe the strengths that this individual presents and how they contribute to the person's ability to adapt and enjoy life?**

2. a) How does the person communicate?

( ) words, ( ) sentences, ( ) sign language, ( ) picture boards. ( ) blissymbols. ( ) gestures, ( ) behaviors

Describe:

Does the person have:

i. ***( ) an accessible means to communicate (picture board)***
ii. ***( )communication that results in desired attention from others***
iii. ***( ) communication that results in desired outcomes***
iv. ***( ) other***

Does the person make his/her physical needs known? How?

Does the person make feelings known? How?

Does the person communicate preferences and choices? How?

Can the person indicate need for help? How?

Does *the person express needs behaviourally? How?*

3. **Does the individual experience difficulty in dealing with some situations, how is it manifested?**

4. **What skills does the person use to relax/calm?**

5. **What coping mechanisms help him/ her to cope?**

6. **Have there been habilitative programmes in place for the individual to increase independence, adaptation or as replacement for challenging behaviours? If so what are they, were they effective and are they still advised?**

7. **What habilitative elements should be present in the new setting? (i.e. teaching communication or coping skills etc.)**

STEP IV: SOCIOCULUTRAL FACTORS

1.

   a. **Are there situations where the individual experiences more or less satisfaction/ dissatisfaction in the day?**

   b. **Are there times of the day when the person experiences more or less satisfaction/ dissatisfaction?**

2. **Are any of these situations associated with dissatisfaction for the person:**

( ) if there is excessive stimulation
( ) following requests or directives
( ) following a demand to do a task
( ) when doing difficult/challenging tasks
( ) when it is noisy
( ) when there is excessive activity
( ) when it is crowded
( ) when teased/provoked by others
( ) in the presence of specific people
( ) in specific settings/activities
( ) at specific times of the day
( ) when situations are unfamiliar
( ) when situations are frightening
( ) when changing to a less desired activity
( ) when in a prolonging activity
( ) at low activity time
( ) at low reinforcement time
( ) when reinforcement is diverted elsewhere
( ) when others are reinforced for their behavior
( ) when a preferred/desired activity is ending
( ) in presence of preferred people
( ) if communication is ignored or request denied
( ) if stopped/interrupted from a desired activity
( ) if praised

Describe in more detail those situations that apply.

3. What interactional / environmental changes might create a situation more suited to the needs of the individual?

( ) reducing/altering approach to or number demands
( ) changing activities or timing of activities
( ) providing choice of activities
( ) leave alone
( ) increased time for personal comfort needs
( ) changes in meals, toileting, rest routines
( ) reduce demands at vulnerable times
( ) letting the person do anything desired
( ) providing choices of activities

( ) increased personal support time
( ) increased access to reinforcers
( ) greater access to desired activities & materials throughout the day
( ) increased opportunity to engage in stimulating activities
( ) increased/partial participation in more activates
( ) more access to materials
( ) more access to leisure activities or hobbies
( ) other

Describe in more detail:

4. How does the person react:
( ) when hungry, thirsty, tired, ill
( ) before or during menses
( ) when afraid, tense or anxious
( ) just before or after seizures

For each item checked, describe in detail:
When hungry, she can verbally indicate the need to eat

5. **Does the person appear more satisfied:**
( ) when alone
( ) independent of who is present
( ) in routine/familiar/less active situations
( ) when in unchallenging situations

To those checked above, describe each:

6. **Does the person participate in the community? What activities are valued by the individual? What activities present challenges? Are there specific community social situations that are problematic? How are safety issues assured when in the community?**

7. **Does the person have known hobbies/ interests/ sporting activities? If you allowed this individual to do whatever he/she wanted what would it be?**

8. **Does the person show spiritual needs (participation in religious activities/ observation of special days or holidays)? How are these best met?**

STEP V. BEHAVIOURAL CONCERNS

1. **What are the behavioural concerns if any? If none proceed to step VI.**

2. **Why is it seen as a problem?**
   - *a. ( ) occurs too frequently (how frequent?)_____*
   - *b. ( ) occurs for long periods of time (duration?)_____*
   - *c. ( ) is very intense (specify)_____*
   - *d. ( ) is not appropriate to place, time, people etc. (specify)_____*
   - *e. ( ) causes damage/health risk to individual or others (specify)_____*
   - *f. ( ) causes damage to property (specify)_____*
   - *g. ( ) interferes with the individual's opportunity to socialize, learn or be involved in*
     - *i. Desired activities (specify)_____*
   - h. *( ) is disruptive to others (specify)_____*

4. **Expand on any of the above:**

5. **Does the behavior:**
   - *i. ( ) occur in isolation*
   - *j. ( ) cluster with other behaviors*

k. ( ) have early signs that signal you it is going occur
l. ( ) occur constantly or does it change over time (i.e. cycle)
m. ( ) appear to have changed recently

Describe any of the above you checked:

6. **Has this behavior recently changed and if so how?**

7. **Have there been other changes apparent in the individual at this time? (i.e., physical appearance, interests, sleep, appetite, energy, responses to people or the environment)?**

What possible functions does the behavior serve:

Does the behavior serve to:	**Specific functions**	**Possible Hypotheses**
allow the individual to avoid/escape/ remove or delay an undesired	*( ) attention, interactions* *( ) activity or task* *( ) demands* *( ) setting events (i.e., noise/lights/crowds)* *( ) other*	*Negative Reinforcement*
Gain desired	*( )attention, counseling, physical intervention, reprimands, individual time* *( ) tangible outcomes (i.e., food/object)* *( ) change in activity* *( ) continence of an activity*	*Positive Reinforcement*
Provide	*( ) interruptions to discomfort* *( ) relief from discomfort* *( ) physical needs*	*Negative Reinforcement*

Provide	*( ) sensory stimulation*	*Positive Reinforcement*
Communicate	*( ) a desire to escape and avoid a situation/ person/event*	*Negative Reinforcement*
	( ) pain, anxiety, fear, hunger, or discomfort	*Negative Reinforcement*
	( ) desire for attention, change of activity, change in reinforcement	*Positive Reinforcement*
	( ) no intention to communicate	

8. **Currently what reaction does the behavior appear to most often receive? Describe:**

9. **Does the behavior result in gaining the person:**
   - *i. ( ) accelerated attention*
   - *ii. ( ) physical contact*
   - *iii. ( ) gaining access to desired possessions*
   - *iv. ( ) change of activity or access to an activity*
   - *v. ( ) individual supervision*
   - *vi. ( ) counseling by staff*
   - *vii. ( ) access to preferred people*
   - *viii. ( ) help or comfort*
   - *ix. ( ) a tangible item*
   - *x. ( ) is scolded or reprimanded*
   - xi. *( ) intervene to interrupt the behavior*

10. **Does the behavior result in changing/reducing some situations such as:**
    - *( ) activity is discontinued*
    - *( ) interaction is stopped*
    - *( ) person is removed from situation or time out*
    - *( ) others removed from situation*
    - *( ) activity is delayed*
    - *( ) demands are reduced*
    - *( ) noise is reduced*

11. **Was the response to the behavior consistent across time and people? If not describe.**

12. **Did the observations support the hypotheses regarding the interviews with caregivers? If so what is the motivation(s) for the behavior(s)?**

STEP VI. COMPARISON OF HISTORY AND INTERVIEW DATA WITH ESSENTIAL PLAN

	Elements that should be considered in Transitional Planning to ensure positive quality of life	*Elements that are in the Essential Plan*	*Discrepancy*	*Comments*
Medical/ Psychiatric (including health/ mobility/ fitness/ nutrition)				
Socio-Environmental a) Social (meaningful relationships) b) Physical "at home in environment"/ safety/ privacy) c)				

Programmatic (purposeful meaningful daily activities) d) Leisure (activities/ hobbies) d) Spiritual (values/ celebrations) e) Community Inclusion				
Psychological (initiating positive behaviour/ sense of self/coping skills/ personal expression and choices and opportunity for learning and change)				
Behavioural (minimization of distress)				

***Further* considerations for placement observations:**

Appendix D: Interview Questions

Appendix D1

INTERVIEW QUESTIONS: FRONT LINE STAFF (Community)

Case Number:
Date:
Period of Interview: Post/ 3 month/6 month/12 months

Adjustment/adaptation to the transition

1) How well is the individual adapting to the new situation?

2) Would you say the person has accepted the transition?

3) If so how long did it take for the transition to be accepted?

4) Has the person developed strong relationships with staff? Can you give me some examples?

5) Has the person developed strong relationships with peers? Can you give me some examples?

Setting and Supports

6) How appropriate do you feel this setting is for the individual? Why?

7) What is the current ratio of staff to this individual during the day (:); at night (:), in the community (:)? %

8) Do you think the staffing is sufficient to meet the person's needs?

9. What type of training has the staff received in the past few months to support the needs of this individual? Is it sufficient and appropriate? Is there need for more training?

10) Does the person see a professional (name professional), and if so how often? If these re-new or if there are changes in professional support why were services added or deleted?

Physician	
Dentist	
Behavior Therapist	
Psychiatrist	
Physiotherapist	
Occupational Therapist	
Speech/ Communication	
Social Worker	
Neurologist	

Psychologist	
Other	

11)Are there services that are needed but not available?

12)Would you say the support services are sufficient and appropriate for the person?

C. Daily Routines

13)What time of day does the person awake on weekdays___ weekends___Does the person awoken or does he/she awake themselves?

14)What time is breakfast on weekdays_____weekends_____? What time is lunch on weekdays _____ weekends? What time is dinner on weekdays_____ weekends ?

15)Does the person help in meal preparation? How?

16)How is his/her appetite? Are there any challenges at mealtime?

17)What time is bedtime on weekdays_____ weekends_____? Who initiates bedtime?

18)When does the person bathe? Daily, every other day, weekly. Is bath at a scheduled time or initiated by the individual?

19)How is the person's sleeping patterns? Does he/she awake during the night or is woken by staff? Why?

D. Activities and Community Inclusion

20)Are you pleased with the amount and appropriateness of meaningful/personally fulfilling things the person has to do each day?

21)Are these new interests?

22)Does the individual exercise daily?

23)What daily household activities does the person participate?

24)Does the person have a day programme? Where is it? Is it individualized or participation in a group activity? Do you think it is a good match for the individual?

25)Has the person shown increase in independence since moving to your agency or since our last visit? Can you give examples?

26) I will name some activities and ask you to say if the person does these things frequently (monthly), sometimes (less than once a month) or never.

	Frequently (at least once a month)	Sometimes or rarely (less than once a month)	Never
Dining in a restaurant			
Receiving visits from friends			
Receiving visits from relatives			
Visiting friends (outside the home)			
Visiting relatives			
Telephone calls to or from family			
Telephone calls to or from friends			
Socialization with peers			
Going to place of worship			
Going to a movie			
Going shopping			
Going on a holiday			
Attending a concert or play			
Watching a sporting event			
Visiting a social club			
Visiting a park or going for a walk			
Going to a barber/hairdresser			
Are there other activities the person does that I have not mentioned?			

27) How is the person actively <u>included</u> in the community? What leisure and community activities does the person regularly participate?

28) Has the individual had contacts with neighborhood or general community?. Have these contacts been positive or negative?

29)Has family and friend contact has changed since the move or last evaluation?

30)Since placement or our last evaluation have family or friends helped the individual relative to advocacy, support/advice, or emotional support?

31)Has the individual's new setting affected the relationships with family and friends in the past few months? Can you give some examples?

32)Has the individual gone with family or friends on an overnight stay since the transition or last evaluation?

33)Has the individual shared meals with family or friends since the transition?

E. Changes since Transition

34)What choices about his/her own day has the person been making? Is it increasing?

35)Has the person experienced a change in medical status/ health? Please explain.

36)Has the person experienced behavioral challenges since transition or since last evaluation? Are the challenges greater or less than expected from the Essential Elements Plan or previous period?

37)How are they being managed? Are the strategies working?

38)Has the individual required police contact? If so please elaborate.

39)What are the biggest changes in the individual since transition/ last evaluation?

- Health or mental health
- Interests Adaptive skills
- Self-care
- Communication
- Social Skills

- Other... please give examples

F. Quality of Life

39) Tell me about the individual's quality of life today.

40) What do you think is the most important factors responsibility for the quality of life? Would you recommend things to improve his or her quality of life? Are there problems in accessing additional resources and if so why?

41) What new plans and goals do you have for this person today that you did not have previously?

42) Is there anything else you want to add to help us understand the person?

Summary

43) At this time if you would have changed anything for this person what would it have been? What are the lessons you wish to send forward to others?

Appendix D2

INTERVIEW QUESTIONS: Family

Case Number:

Date:

Period of Interview: Post/ 3 month/6 month/12 month

1. How are you feeling about the placement at this time?

2. Has your family member adapted well to the new physical environment?

3. Has your family member adapted well to living in a smaller setting?

4. How are his/her relationships with the staff? With others living in the home?

5. Would you say the location is a good fit for your family member?

6. Are you satisfied that the design of the home is appropriate for your family member?

7. Are you satisfied with the staffing arrangements?

8. Does your family member have the level of professional/ medical supports recommended?

9. Are you pleased with the quality and access to needed professional/ medical supports?

10. Is there good communication with the new agency?

Are you geographically closer to your family member?

12. How often are you able to visit? Call? Have your family member visit?

13. What word describes the quality of life of your family member now?

14. Is anything happening that you did not anticipate?

Appendix D3

INTERVIEW QUESTIONS: AGENCY ADMINISTRATIVE STAFF

Case Number:
Date:
Period of Interview: Post

1. Did you feel prepared to accept this person into the programme?

2. What supports were you able to arrange to have in place when the person moved?

3. What adaptations have you made to the setting to accommodate this person? Have you been given supports to enable these adaptations to occur?

4. What specialized staff and training has been done? Are you being funded appropriately for this?

5. Has the planning been individualized? If so how?

6. How has the family been involved? How often will you communicate with them after the transfer?

7. How confident are you that you will be able to successfully support this individual?

8. Does he or she pose any challenges that are unusual for your agency? If so what are these challenges? How do you plan to overcome them?

9. Do you feel the Essential Elements Plan captured the needs of the person?

10. How does your transitional plan align with the Essential Elements Plan? How will it be actualized? Where if anywhere will it differ?

Appendix D4

INTERVIEW QUESTIONS: FACILITY PLANNERS

Case Number:
Date:
Period of Interview: Post

1. Did you feel that the Essential Elements plan was ready for the person to move into the community? Are you confident that the implementation plan based on the Essential Elements Plan is in place?

2. What supports were arranged for when the person moved? Are there supports that should be in place but were not accessible? Why?

3. What adaptations have been made to the setting to accommodate this person? Has the agency been given supports to enable these adaptations to occur?

4. What specialized staff and training has been done? Are they being funded appropriately for this staffing ratio and training.

5. Has the planning been individualized? If so how?

6. How has the family been involved? How often will you communicate with them after the transfer?

7. How confident are you that the chosen agency will be able to successfully support this individual?

8. Does he or she pose any challenges that are unusual for this agency? If so what are these challenges? How do you see the agency overcoming them?

9. Do you feel the Essential Elements Plan captures the needs of the person?

10. How does the transitional plan align with the Essential Elements Plan? How will it be actualized? Where if anywhere will it differ?

11. How do you think this person is doing in the community program that has been designed? Please tell me about it.

12. What supports are in place for the person currently? Are they sufficient? Are they accessible? Are their additional supports needed? Were some supports recommended but not needed. If so why?

13. How have the adaptations to the setting to accommodate this person worked out?

14. Are you finding there were other adaptations that were needed or that some of the adaptations you made were unnecessary?

15. Do you feel the staffing is still sufficient? Do staff need additional training? Have they received any?

16. How has the individualized planning paid off or has it?

17. How has the family been involved? How often will you communicate with them?

18. How confident are you now that you will be able to successfully support this individual?

19. Does he or she pose any challenges that are unusual for your agency? If so what are these challenges? How do you plan to overcome them?

20. Do you feel the Essential Elements Plan still captures the needs of the person?

21. How does your current plan align with the Essential Elements Plan? Where if anywhere does it now differ?

22. At this time if you would have changed anything for this person what would it have been? What are the lessons you wish to send forward to others?

Appendix E

OBSERVATION SHEET

Throughout the course of your visit with the individual maintain an active observation sheet of events that occur (observing approximately the 1st 10 minutes of each hour you spend). Observation times should be approximately 8 hours and include at least one mealtime.

Time	Setting and Activities	Observations / Interactions

Appendix F

DISCREPANCY ANALYSIS BETWEEN OBSERVATION AND ESSENTIAL ELEMENTS PLAN

1. A. Is the type of setting group home ( ), apartment ( ), family home ( ) other ( )
   Consistent with that described in the Essential Elements Plan and Transitional Plan

   If not why was a change recommended?

2. Describe the home in detail.

   How many people with disabilities live with the person in his or her home (unit)?

3. Describe the other people in the home and the interactions observed.

4. Does the person have a room of his or her own? Yes No Is this consistent with the Essential Elements Plan and if not why?

5. Describe the room. Is the room consistent with what was recommended in the Essential Elements and Transitional Plan and if not why?

6. What is the staffing and is it consistent with recommendations in the attached Essential Elements Plan? Yes No If not why?

7. From the records and interviews is the access to professional services as recommended in the Essential Elements Plan and if not why? Are they adequate and sufficient? What else is needed? Why are they not accessed?

Professional Services	**Currently receives**	**Frequency of Access**	**Were these in the Essential Plan?**	**Why were professional services added or deleted from the Plan?**
Physician				
Dentist				
Behaviour Therapist				
Psychiatrist				
Physiotherapist				
Occupational Therapist				
Speech/ Communication				
Social Worker				
Neurologist				
Psychologist				
Other				

8. Were these activities identified in the Essential Elements Plan? *Yes/ No*

9. Are their activities recommended in the Essential Elements Plan that are not available or accessible to the person? *Yes/ No.* If so why?

10. Were the above activities recommended in the Essential Elements Plan? Yes / No

11. Have activities that were recommended in the Essential Elements Plan been accessed? *Yes / No* If not why?

12. How relevant is the Essential Elements Plan to the person today? *Not relevant Somewhat relevant Very relevant*

Appendix G

BEHAVIOR / MEDICAL STATUS REPORT

Field notes from visit: Case Number:

Date: Pretransition/Post transition/ 3 mo., 6 mo. 12 mo.

Medical Status for previous 3 month period (note any appointments, hospitalizations, status changes in medication or diagnoses)

Behavioural Status for previous 3 month period (note incident reports, note behavioural data and changes in behavioural profile or programming during this period, including any police involvement)

Other notations from file of significance (family visits, outings, restrictions, changes in routines etc.)

Note any changes in routines, staffing, expectations, and supports that have occurred since previous field note and identify rationale and impact.

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